
Vital and Health Statistics

Development, Methods, and Response Characteristics of the 1986 National Mortality Followback Survey

Series 1:
Programs and Collection Procedures
No. 29

This report describes the methods employed in the 1986 National Mortality Followback Survey. This survey is based on information obtained from relatives of decedents and from health care facilities used by the decedents in their last year of life.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
Centers for Disease Control and Prevention
National Center for Health Statistics

Hyattsville, Maryland
May 1993
DHHS Publication No. (PHS) 93-1305

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Suggested Citation

Seeman I, Poe GS, Powell-Griner E. Development, methods, and response characteristics of the 1986 National Mortality Followback Survey. National Center for Health Statistics. Vital Health Stat 1(29). 1993.

Library of Congress Cataloging-in-Publication Data

Development, methods, and response characteristics of the 1986 National Mortality Followback Survey.

p. cm. — (Vital and health statistics. Series 1, Programs and collection procedures; no. 29) (DHHS publication; no. (PHS) 93-1305)

"January 1993."

Includes bibliographical references.

ISBN 0-8406-0471-8

1. National Mortality Followback Survey (U.S.) 2. Health surveys—United States—Statistical methods. I. National Center for Health Statistics (U.S.) II. Series. III. Series: DHHS publication; no. (PHS) 93-1305.

[DNLM: 1. National Mortality Followback Survey (U.S.) 2. Data Collection—methods. 3. Mortality. W2 A N148va no. 29]

RA409.U44 no. 29

[RA407.3]

362.1'0723 s—dc20

[304.6'4'0723]

DNLM/DLC

for Library of Congress

92-48960
CIP

For sale by the U.S. Government Printing Office
Superintendent of Documents
Mail Stop: SSOP
Washington, DC 20402-9328

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Symbols

---	Data not available
. . .	Category not applicable
—	Quantity zero
0.0	Quantity more than zero but less than 0.05
*	Figure does not meet standard of reliability or precision (100 or fewer estimated deaths; relative standard error of 30 percent or more)

Development, Methods, and Response Characteristics of the 1986 National Mortality Followback Survey

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Introduction

This report describes the development process, the methods employed, and the response characteristics for the 1986 National Mortality Followback Survey (NMFS). This introduction provides a brief overview of the origin, purposes, nature, and contents of the survey. The next section describes the process used in the development of the survey and significant aspects of the results of the pretest. The third section describes the main survey: sampling of death certificates, the collection and processing of survey data, the production of national estimates, the approximation of sampling errors, the nature of non-sampling errors, and quality control measures employed. The fourth section examines response rates for informants and for facilities, by relevant characteristics.

Background of the 1986 National Mortality Followback Survey

Mortality statistics in the United States are based on information coded by the National Center for Health Statistics (NCHS) from copies of the original death certificates received from State registration offices, and on state-coded data provided to NCHS through the Vital Statistics Cooperative Program (VSCP) (1). These data are invaluable in understanding mortality characteristics and trends. To expand on these data, NCHS periodically conducts mortality followback surveys. NCHS developed

the mortality followback survey methodology in the 1960's out of its interest in learning more about mortality than is available from death certificates, its interest in evolving useful statistical methodologies, and its unique access to the total universe of deaths in the United States (2).

The followback surveys collect information on a variety of subjects, including the use of health services during the last year of life, patterns of lifetime behavior that may affect longevity, socioeconomic circumstances of the decedent, environmental influences on health, and other aspects of life style that may influence the cause and timing of death. This information is secured from the next of kin or some other person familiar with the decedent's life history. The followback survey is a cost-effective method for obtaining useful information for the study of the epidemiology of disease, demographic trends in mortality, and other health issues. The sampling universe is all resident deaths in the United States in a given year. Information on the decedent can be sought by mail questionnaire and by telephone or personal interview.

The four mortality followback surveys conducted during the 1960's by NCHS produced national data on characteristics of decedents, including many characteristics not available from other sources (table A). The 1961 survey secured information on the use of hospital and institutional care in the last year of life (3,4). The 1962-63 survey obtained information on socioeconomic differentials in mortality (5). The 1964-65 survey provided data on expenditures for health care during the last year of life, sources of payment, and health insurance coverage of decedents (6,7). The 1966-68 survey provided evidence from a national probability sample of deaths on the link between smoking and cancer mortality (8,9).

The 1986 NMFS is the fifth mortality followback survey conducted by NCHS. It focused on a nationally representative sample of adults 25 years of age or over who died in 1986. While all 50 States and the District of Columbia granted their approval for use of a sample of the

NOTE: This report was prepared in the Division of Vital Statistics. Steven Botman, Office of Research and Methodology, provided guidance in the design of the sampling procedure and the information on sampling error and estimation; Arlene Siller, Office of Vital and Health Statistics, provided guidance on computer programming; George Wolfe, Division of Health Care Statistics, provided guidance on table preparation; Betty Smith, Statistical Resources Branch, Division of Vital Statistics, provided content review. This report was edited by Margaret Avery and typeset by Jacqueline M. Davis, Publications Branch, Division of Data Services.

Table A. Major subjects covered in the five NCHS National Mortality Followback Surveys, by year of survey: United States, 1961-68 and 1986

Subject	1961	1962-63	1964-65	1966-68	1986
Days of hospital care, last year of life	X				X
Place of death	X				X
Family income, in year prior to death	X	X	X	X	X
Sources of income		X	X	X	X
Highest grade of school completed	X	X			X
Institutional care (other than hospital)		X	X		X
Whether person died in hospital	X	X			X
Household of decedent		X	X	X	X
Hospital insurance			X		X
Insurance for surgeon's bill			X		X
Amount of hospital bill			X		X
How much insurance paid			X		X
Amount paid by children			X		X
Out-of-pocket expenses					X
Operations performed	X	X			X
Diagnoses	X				X
Family assets			X	X	X
Smoking practices				X	X

NOTE: NCHS is National Center for Health Statistics.

death certificates in the NMFS, Oregon is not included in the NMFS due to that State's respondent consent requirements. The data are therefore representative of deaths of adult residents in the United States excluding Oregon.

The universe for the 1986 NMFS was composed of all death certificates for 1986 decedents 25 years of age or older filed in the United States. The sampling frame comprises death certificates selected from the 1986 Current Mortality Sample (CMS). The CMS was a 10-percent systematic sample of death certificates received by the state vital statistics offices and transmitted to NCHS about 3 months after the deaths occurred (See "Data processing"). CMS records were selected for each month of the year. To meet specific research needs, 2,274 of the sampled death certificates were selected with certainty (table B). Selected populations in the remaining CMS

certificates were oversampled so that reliable numbers of deaths in these important cohorts could be obtained. Black decedents were oversampled 2.9 times, and decedents under age 55 were oversampled 3.1 times.

The 1986 NMFS focused on four subject areas:

- Socioeconomic differentials in mortality
- Prevention of premature death by inquiring into the association between risk factors and cause of death
- Health care services provided in the last year of life
- Correspondence between certain items reported on the death certificate and those reported on the informant questionnaire

Information was secured from two sources: the next of kin of the decedent or some other person familiar with the decedent, and the health care facilities used by the decedent in the last year of life. Questionnaires were mailed to a sample of 18,733 persons identified as informants on the death certificates of individuals who died in the United States in 1986. If, as in a small number of cases, no informant could be identified from the death certificate, efforts were made to locate the next of kin of the decedent. In addition, brief questionnaires were mailed to all hospitals, nursing homes, and other health care facilities decedents were reported to have used in their last year of life.

The 1986 NMFS differed in several respects from the four previous mortality followback surveys. First, the number of deaths included in the sample was greater than in any previous NMFS. The sample size was nearly 1 in 100 deaths, compared with 1 in 260 to 1 in 330 in previous surveys. Second, the subject areas covered by the survey were considerably broader than those in prior surveys so that the questionnaire was much longer than its four predecessors. Third, as described in "The formal pretest," the pretest included several methodological experiments. Fourth, a consent form to permit the release of information from health care facilities was included to increase

Table B. Strata selected with certainty for causes of death by sex, age, and race: National Mortality Followback Survey, 1986

Cause of death and ICD-9 code	Sex	Age	Race
Cardiovascular deaths			
Ischemic heart disease410-414	Male	25-44 years	All
Ischemic heart disease410-414	Female	25-54 years	All
Cancer deaths			
Malignant neoplasm of nasopharynx147	Male and female	25-64 years	White
Malignant neoplasm of small intestine, including duodenum152	Male and female	25-74 years	White
Malignant neoplasms of liver and intrahepatic bile ducts155	Female	25-49 years	All
Malignant neoplasms of nasal cavities, middle ear and accessory sinuses160	Male	25-74 years	White
Malignant neoplasm of male breast175	Male	25-74 years	All
Malignant neoplasms of thyroid gland and other endocrine glands and related structures193-194	Male and female	25-64 years	White
Asthma deaths			
Total493	Male and female	All	All
All deaths			
Total	Male and female	All	American Indians, Aleuts, and Eskimos

NOTE: ICD-9 is the Manual of the International Statistical Classification of Diseases, Injuries, and Causes of Death, based on the recommendations of the Ninth Revision Conference, 1975 (Geneva: World Health Organization, 1977).

facility response. Fifth, this project involved active participation by a number of other Federal agencies. Finally, in addition to mailed questionnaires and personal interviews used in previous surveys, the data collection process included telephone interviews. Still, a number of subject areas covered in the prior surveys were also included in the 1986 study to maintain maximum comparability and to permit some trend analysis (table A).

In addition to the main survey described, a special study was incorporated in the 1986 survey at the request of the National Cancer Institute, one of the cooperating agencies in the survey. Approximately 1,500 records of all deaths in the year 1985 from specific cancer sites with rare occurrences were drawn and surveyed. Data from these cases are not included in the 1986 NMFS Public-Use Data Tape, and are not included in the discussion that follows.

The 1986 NMFS was developed collaboratively by NCHS and other agencies. Guidance on content and methods was furnished by an NCHS Work Group

composed of representatives of 10 offices of the Center (See "Participation of cosponsors and advisory groups"). Other agencies of the Public Health Service, the Department of Health and Human Services, and the Veterans' Administration participated in planning the survey and providing funding through NCHS's Reimbursable Work Program.

Availability of data and findings

A 1986 National Mortality Followback Survey Public-Use Data Tape (PB 90-5011800) with accompanying documentation may be purchased from the National Technical Information Service, U.S. Department of Commerce, 5285 Port Royal Road, Springfield, Virginia 22161. Analyses of the 1986 NMFS are being published as NCHS reports and as journal articles, and are being presented at meetings of professional organizations.

Development of the survey

Selecting the foci of the 1986 survey

Criteria for selecting the subject matter foci of the 1986 National Mortality Followback Survey (NMFS) included (1) the relevance of the proposed subject to broad public health concerns and to the policy and programmatic issues and interests paramount in the Public Health Service (PHS) and the Department of Health and Human Services (DHHS); (2) capitalizing on the uniqueness of the population; (3) the likelihood of the results being valid, reliable, and generally useful; (4) the impact of the nature, length, complexity, and sensitivity of the content on response rates; and (5) maintaining some continuity with prior mortality followback surveys. Particular attention was paid to disease prevention, one of the major health policy issues of concern to the PHS and the DHHS, as reflected in two reports describing the PHS initiative on health promotion and disease prevention (*Healthy People* (10), and *Promoting Health/Preventing Disease: Objectives for the Nation* (11)).

Out of these considerations and after consultations with two advisory groups to the survey, agreement was reached on four subject areas: (1) socioeconomic differentials in mortality, (2) prevention of premature death by inquiring into the association between risk factors and the cause of death, (3) health care services provided in the last year of life, and (4) the reliability of certain items reported on the death certificate.

Participation of cosponsors and advisory groups

Recognizing the 1986 survey's potential for providing data useful to a variety of missions and interests, a number of Federal agencies participated in a Consulting Group (listed below) to discuss the project. Of these agencies, eight (designated by double bullets) agreed on a plan for cosponsorship and funding:

- Administration on Aging, DHHS
- Alcohol, Drug Abuse, and Mental Health Administration, Office of Planning, Policy Analysis, and Legislation, DHHS
- Centers for Disease Control, DHHS
- Food and Drug Administration, DHHS
- Health Care Financing Administration, DHHS

- Indian Health Service, DHHS
- Office of the Deputy Assistant Secretary for Health, Health Promotion, and Disease Prevention, DHHS
- National Cancer Institute, DHHS
- National Heart, Lung, and Blood Institute, DHHS
- National Institutes of Health, Office of the Director, DHHS
- National Institute on Aging, DHHS
- National Institute on Alcohol Abuse and Alcoholism, DHHS
- National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases, DHHS
- National Institute of Child Health and Human Development, DHHS
- National Institute on Drug Abuse, DHHS
- National Institute of Mental Health, DHHS
- Social Security Administration, DHHS
- Veterans Administration

A ninth sponsor, the Office of the Assistant Secretary for Planning and Evaluation in the Office of the Secretary of DHHS, provided funding as the survey progressed.

A decision was also reached to formalize the process for involvement of other units of the National Center for Health Statistics (NCHS) in the development and execution of the survey. An NCHS Work Group was formed for consultation and for coordination of the NMFS with other relevant NCHS surveys, including common wording of items on the 1984 Supplement on Aging of the National Health Interview Survey and clarification of common interests with the 1985 National Nursing Home Survey.

Pretest procedures

Several pretest procedures were determined to be essential, particularly in light of the long period since the last NMFS was conducted. These included a pilot test of the questionnaire with a bereavement group, a minitest, and a formal pretest, described below.

Survey design is enhanced when, at an early stage, a sample of persons who correspond to the potential respondents react to the ideas being considered. For the 1986 NMFS, this step was taken through a discussion held at a hospice in Northern Virginia with nine members of a

bereavement group who met regularly following the death of a family member. Group members filled in and discussed an early draft of the questionnaire and reviewed proposed procedures. This process provided valuable guidance at an early stage in the survey design.

A minitest was held after further planning but prior to the formal pretest. The purpose of the minitest was to assess the reactions to the proposed study instrument and procedures by respondents most similar to those to be surveyed. Interviews with the next of kin of recent decedents were conducted in the Washington, D.C., area. These decedents were identified from death certificates in the manner that would be followed in the pretest and the main survey. The informant was handed a questionnaire by a Census Bureau interviewer and asked to complete it as though it had come in the mail, while the interviewer waited. The interviewer then discussed the completed questionnaire with the respondent to learn how the respondent reacted to the questions and the procedures. Members of the survey staff and of the NCHS Work Group attended many of these interviews. A detailed analysis of responses to specific questionnaire items assisted in the revision of the instrument.

The formal pretest

The formal pretest was designed to fulfill three purposes: (1) To select the most appropriate means of identifying and tracing the appropriate informant, (2) to test procedures for achieving a high level of response, and (3) to test the questionnaire content and format.

The U.S. Bureau of the Census conducted the data collection both for the pretest and for the main survey.

Four States—Illinois, New Mexico, Vermont, and Virginia—were selected for the pretest to provide geographic, racial, and ethnic diversity. The registrars in these States approved the followback on the death certificates from decedents in their States. A sample of adult deaths in September and October 1984 was selected for survey about 6 months after the death. Deaths of black decedents were oversampled 1.8 times the sampling for white decedents, and, because oversampling of heart disease deaths was planned for the main survey, all deaths from Ischemic heart disease at ages 25–44 were selected. A total of 1,363 records was selected, of which 3 were inadvertently dropped from the pretest before the mailing.

The person designated as the “informant” on the death certificate was the preferred primary source of information about the decedent. This individual (usually the next of kin) provides the personal facts about the decedent to the funeral director who completes the death certificate (except for the medical certification). Of the 1,363 pretest sample certificates, 618 (or 45.3 percent) contained the name and address of an informant. However, there were six States in which the death certificate form did not provide a space for the address of the informant, making contact with this person difficult. One such State, Virginia, was deliberately included in the pretest so that tracing techniques could be tested. It was

also discovered during the pretest that many certificates, particularly in Illinois, listed a medical or hospital record as the informant rather than the name and address of the person who gave the information to the facility. Inspection of these certificates showed that on 244 the name of a surviving spouse was listed elsewhere on the record (table C). In such cases, a decision was made to mail the questionnaire to the surviving spouse at the usual residence of the decedent.

The primary procedure used to secure the names and addresses still missing was to telephone the funeral director or write to him or her if he or she requested the inquiry in writing. There were 501 records (or 36.8 percent) of the sample to be queried. Response was received from the funeral director for 401 records. This process identified a person to receive the questionnaire for 92.7 percent of the sample certificates. For the remaining 100 cases, the questionnaire was addressed to “Next of Kin” of the named decedent at the decedent’s usual address.

The procedure used for the pretest consisted of the following steps:

1. About 6 months after the death, a questionnaire and a cover letter were mailed by first-class government-paid mail to the informant named on the death certificate, the surviving spouse, or other informant as described above. A postage-free return envelope was included.
2. Ten days later letters were mailed to informants, thanking them if they had returned the questionnaires and reminding them to do so if they had not.
3. One month after the initial mailing, a second copy of the questionnaire was mailed to nonrespondents.
4. Four weeks after the second mailing a telephone call or personal interview was attempted to reach nonrespondents in the two large States in the sample, Illinois and Virginia. In the two smaller States, New Mexico and Vermont, only the telephone was used to reach nonrespondents.

In the pretest, the informant on the questionnaire was a close relative of the decedent in 82.8 percent of the cases (table D). A spouse was listed for 34.2 percent of the decedents, and a divorced spouse on 0.3 percent. The informant was a son or daughter for another 30.4 percent. The information was furnished by a decedent’s sibling in 9.6 percent of the records and by a decedent’s parent in 8.6 percent. Other relatives responded in 13.5 percent of the inquiries, and a nonrelative in 2.4 percent. The relationship was not stated for 1.0 percent of the replies.

Although the pretest sample was a stratified, systematic, random sample of all deaths for the chosen months in the four States surveyed, it was not designed to be a probability sample of all adult deaths in the United States. Nevertheless, a comparison was made between the deaths in the sample and all adult deaths in the United States for 1984 (table E). It showed that the proportion of all deaths in the sample did not differ significantly from U.S. deaths

Table C. Number and cumulative percent distribution of informant identification by method of inquiry, according to State of death: National Mortality Followback Survey pretest, 1986

State of death	Total in sample	Original complete	Spouse identified	Required query	Funeral director response by phone	Funeral director response by mail	Total adequate identification
Number							
All informants	1,363	618	244	501	359	42	1,263
Illinois	843	505	111	227	107	31	754
New Mexico	85	83	1	1	1	—	85
Vermont	35	30	3	2	1	—	34
Virginia	400	—	129	271	250	11	390
Cumulative percent							
All informants	100.0	45.3	63.2	—	89.6	92.7	92.7
Illinois	100.0	59.9	73.1	—	85.8	89.4	89.4
New Mexico	100.0	97.6	98.8	—	100.0	100.0	100.0
Vermont	100.0	85.7	94.3	—	97.1	97.1	97.1
Virginia	100.0	—	32.3	—	94.8	97.5	97.5

in terms of sex or age. However, there was a larger percent of black decedents in the pretest sample, primarily because of the selection of Virginia and Illinois as pretest States, both having larger-than-average black populations.

Methodological experiments in the pretest

An important decision made early in the planning for the survey was to seek the means to achieve maximum response and to increase general knowledge of survey techniques by conducting four methodological experiments:

- The inclusion or omission of “Don’t know” response boxes
- A long and a short version of the questionnaire
- The use of certified or first-class mail for the second mailing
- Field followup on nonrespondents by telephone or personal interview

In the analysis of the pretest results discussed below, three code categories—“complete interview,” “fail-edit,” and “partial interview”—are considered to be adequate responses or completed questionnaires.

Table D. Number and percent distribution of informants by relationship of informant to decedent as reported on the questionnaire: National Mortality Followback Survey pretest, 1986

Relationship of informant to decedent	Number	Percent distribution
Total	1,158	100.0
Informant was decedent's—		
Husband or wife	396	34.2
Son or daughter	352	30.4
Father or mother	100	8.6
Brother or sister	111	9.6
Divorced spouse	3	0.3
Other relative	156	13.5
Nonrelative	28	2.4
Not stated	12	1.0

(1) *The effect of “Don’t know” boxes*—Since much of the information sought required knowledge and recall of lifelong habits of the decedent, it was expected that many respondents would either not know or not be able to recall requested information. One experiment was devised to measure the effect on the quality of the data of inclusion of response boxes that permitted the informant to check “Don’t Know” (DK) in completing the questionnaire.

Table E. Number and percent distribution of decedents 25 years of age and over by sex, race, and age, according to the 1986 National Mortality Followback Survey pretest sample and 1984 deaths: United States

Sex, race, and age	Decedents in pretest sample	U.S. deaths	Decedents in pretest sample	U.S. deaths
	Number		Percent distribution	
All decedents ¹	1,363	1,944,000	100.0	100.0
Male	699	1,015,415	50.6	52.2
Female	664	928,585	49.4	47.8
White				
Total	1,035	1,709,978	84.6	88.0
Male	514	887,699	41.9	45.7
Female	521	822,279	42.8	42.3
Black				
Total	318	215,027	14.5	11.1
Male	177	116,506	8.1	6.0
Female	141	98,521	6.4	5.1
Other races				
Total	10	18,995	0.8	1.0
Male	8	11,210	0.7	0.6
Female	2	7,785	0.2	0.4
Age				
25–34 years	50	49,928	3.3	2.6
35–44 years	52	62,556	3.4	3.2
45–54 years	82	117,213	5.8	6.0
55–64 years	185	287,355	13.4	14.8
65–74 years	363	476,570	26.0	24.5
75–84 years	371	550,912	28.0	28.3
85 years and over	260	399,466	19.9	20.5

¹Three cases were dropped before the first mailing.

NOTE: Percents may not add to totals due to rounding.

A split-sample test was designed with half of the questionnaires containing DK boxes for almost all of the questions. For the forms without such boxes, the instructions called for putting a question mark in the answer space if they did not know the answer.

The results of the DK test are shown in table F. There was no significant difference between the two forms in the percent of mailed questionnaires returned completed—58.8 percent that contained the DK boxes and 58.2 percent that did not (a critical value of 1.96, a 0.05 level of significance, was used to test comparisons discussed in this report). However, the average percent of items with a DK response was significantly higher for the questionnaire version with the DK boxes at 7.1 percent, compared with 1.9 percent for the version without DK boxes. The average percent of items left blank was a little higher, but not significantly so, for the version without DK boxes: 13.3 percent compared with 11.3 percent. For several specific questions, the presence of a DK box appeared to make an appreciable difference in the volume of substantive responses. For example, for the question on the number of cigarettes smoked, on the forms without a DK box, 87.7 percent had a substantive response, compared with 69.7 percent where a DK box was present.

On the basis of these results, it was concluded that there would be more advantages than disadvantages in omitting DK boxes in the questionnaire for the main survey. Omitting the DK response boxes made the questionnaire simpler, briefer, and less cluttered and did not materially affect the usefulness of the responses. A more complete report of this experiment is described by Poe (12).

(2) *Questionnaire length*—The second experiment dealt with the length of the questionnaire. The participation of many agencies, each of which desired to include specific questions and areas of inquiry relevant to their interests, produced a questionnaire containing 193 response items. Concern about the effect of this magnitude on response levels resulted in agreement to use a split

sample to test the effect of questionnaire length on response rates. Half of the informants were mailed the full questionnaire; the other half received a shorter version containing 135 items. For administrative reasons, this test was conducted only on the second wave (Wave B) of the pretest mailing. After the mailing phase there was a significant difference in response rates for the two forms, with 53.6 percent responding to the long form and 61.2 percent returning a completed short form (table G). However, after the field work interviews, there was no difference in response rates; the long and short forms each had a response rate of 85 percent (table H). The final questionnaire for the main survey contained 158 response items on 24 pages.

(3) *Method of mailing*—The use of certified mail has been demonstrated to be cost effective in mail surveys. On the one hand, the use of certified mail conveys a sense of the importance of the document, since the mail carrier must obtain a signature from someone in the household in order to deliver the envelope. On the other hand, there was concern that the use of certified mail might alienate respondents who had to visit the post office after an unsuccessful attempt at home delivery.

A split-sample test was therefore conducted for the second mailing of the questionnaire when no response was received from the initial mailing. The difference in response following the mailing phase was significant (table J). Substantive responses to the second mailing were received from 37.6 percent of the certified deliveries and from 24.9 percent of the first-class mailings. The refusal rate was also higher for the certified group at 4.3 percent, compared with 1.0 percent for the first class. It is important to observe, however, that the positive effect of using certified mail evaporated following the field work phase of data collection. For the cases sent by certified mail, the final response rate after telephone and personal interviews was 83.4 percent, and for those sent by first-class mail it was 87.2 percent (table K). This experiment is discussed by Poe (13).

Table F. Number and percent distribution of results of mailing by type of response, according to whether "Don't know" box was included: National Mortality Followback Survey pretest, 1986

Type of response	Total	With "Don't know" box	Without "Don't know" box	Total	With "Don't know" box	Without "Don't know" box
		Number	Number		Percent distribution	Percent distribution
Questionnaires mailed	1,360	699	661	100.0	100.0	100.0
Questionnaires returned	874	448	426	64.3	64.1	64.4
Positive response	796	411	385	58.5	58.8	58.2
Completed	755	391	364	55.5	55.9	55.1
Fail-edit	41	20	21	3.0	2.9	3.2
Not informed ¹	16	7	9	1.2	1.0	1.4
New Informant	5	3	2	0.4	0.4	0.3
Informant deceased	5	—	5	0.4	—	0.8
Refused	31	16	15	2.3	2.3	2.3
Postmaster return	16	8	8	1.2	1.1	1.2
No next of kin	5	3	2	0.4	0.4	0.3
No response	486	251	235	35.7	35.9	35.6

¹Informant had inadequate information to respond.

NOTE: Percents may not add to totals due to rounding.

Table G. Number and percent distribution of questionnaires in mailing phase by type of response, according to questionnaire length: National Mortality Followback Survey pretest (Wave B), 1986

Type of response	Total	Long form		Short form ¹		Total	Long form		Short form ¹
		Number		Percent distribution					
Questionnaires mailed, Wave B	812	405		407		100.0	100.0		100.0
Questionnaires returned	508	237		271		62.6	58.5		66.6
Positive response	466	217		249		57.4	53.6		61.2
Completed	447	207		240		55.0	51.1		59.0
Fail-edit	19	10		9		2.3	2.5		2.2
Not informed ²	10	4		6		1.2	1.0		1.5
New informant	5	1		4		0.6	0.2		1.0
Informant deceased	1	1		—		0.1	0.2		—
Refused	15	7		8		1.8	1.7		2.0
Postmaster return	6	4		2		0.7	1.0		0.5
No next of kin	5	3		2		0.6	0.7		0.5
No response	304	168		136		37.4	41.5		33.4

¹The short form was used only in Wave B.

²Informant had inadequate information to respond.

NOTE: Percents may not add to totals due to rounding.

The decision was made to use only first-class mail in the main survey, since there was less risk of alienating potential respondents that way. The higher rate of refusals by certified mail would require more field followup with its greater expense, so the total survey cost would be somewhat higher, but not significantly so.

(4) *Method of field followup*—Of the total of 1,360 questionnaires mailed, 796 were completed and returned by mail, a 58.5 percent mail response rate (table L). The fourth experiment tested the method of field followup for nonrespondents, by comparing telephone interviews and personal interviews. This experiment was conducted for decedents in Illinois and Virginia only, since no personal interviews were conducted in the pretest in New Mexico and Vermont, the two smaller States. Nonrespondents to the two mailings were split into two groups: half assigned to telephone followup and half to personal followup. However, if those assigned to telephone interview could not be reached by phone, the interviewer was instructed to attempt a personal interview. If the primary method was a personal interview, and several attempts were unsuccessful, the interviewer was instructed to attempt a telephone inquiry. In both cases no personal interview was attempted

if the respondent lived more than 50 miles from the interviewer's residence.

The response rates for both methods were very similar, with rates of 76.8 percent for the telephone and 75.4 percent for personal interview (table M). Based on these results and on cost considerations, the procedure selected for the main survey was for a telephone interview to be attempted first, with personal interviews to be used for unsuccessful telephone attempts.

The final pretest response rate after all attempts to contact the informant was 87.1 percent. Refusals accounted for 4.4 percent, and 8.5 percent failed to respond. The final response rates by method of inquiry are shown in table L.

Comments from informants

In a further effort to learn of the reactions of the persons asked to complete the questionnaire, the last page of the form provided space for "Additional answers or comments," with a section headed "Please add any comments or suggestions that you think can help in this study."

All of the 796 completed and 31 of the refusal pretest questionnaires returned by mail were examined for the content in this comment section. Some entry was made on the comment page on a total of 142 questionnaires, 17.2 percent of the mail respondents. The most frequent and generally the most eloquent comments dealt with the health care received by the decedent; this was usually critical of the type of care provided during the last illness.

Other comments either explained the nature of the relationship of the informant to the decedent (often the fact that, because of a limited relationship, the respondent was unable to provide all of the information requested); described the nature of the illness experienced by the decedent, with details about symptoms, the pain experienced, and special problems; or explained why the respondent refused to participate in the survey.

Table H. Number and percent distribution of questionnaires after final results by method of response, according to questionnaire length: National Mortality Followback Survey pretest (Wave B), 1986

Method of response	Long form	Short form ¹	Long form	Short form ¹
	Number		Percent distribution	
Both mailings				
Number mailed	405	407	100.0	100.0
Positive response	217	249	53.6	61.2
Field interview				
Number assigned	168	132	100.0	100.0
Positive response	126	97	75.0	73.5
Total positive response	343	346	84.7	85.0

¹The short form was used only in Wave B.

NOTE: Percents may not add to totals due to rounding.

Table J. Number and percent distribution of second-mailing questionnaires by type of response, according to method of mailing: National Mortality Followback Survey pretest, 1986

Type of response	Total	Certified mail	First-class mail	Total	Certified mail	First-class mail
		Number			Percent distribution	
Questionnaires mailed	780	391	389	100.0	100.0	100.0
Questionnaires returned	300	186	114	38.5	47.6	29.3
Positive response	244	147	97	31.3	37.6	24.9
Completed	228	139	89	29.2	35.5	22.9
Fail-edit	16	8	8	2.1	2.0	2.1
Not informed ¹	11	4	7	1.4	1.0	1.8
New informant	5	5	—	0.6	1.3	—
Informant deceased	2	1	1	0.3	0.3	0.3
Refused	21	17	4	2.7	4.3	1.0
Postmaster return	16	12	4	2.1	3.1	1.0
No next of kin	1	—	1	0.1	—	0.3
No response	480	205	275	61.5	52.4	70.7

¹Informant had inadequate information to respond.

NOTE: Percents may not add to totals due to rounding.

Table K. Number and percent of questionnaires after final results by method of response and use of certified versus first-class mail: National Mortality Followback Survey pretest, 1986

Method of response	Certified mail	First-class mail	Certified mail	First-class mail
	Number		Percent	
Second mailing (split sample)				
Number mailed	391	389
Positive response	147	97	37.6	24.9
Field interview				
Number assigned	211	276
Positive response	145	219	68.7	79.3
Total mailed	681	679
Total positive response				
First mailing (all first class)	276	276
Second mailing (split sample)	147	97
Field interview	145	219
Total response	568	592	83.4	87.2

Table L. Number and percent distribution of inquiries by type of final response, according to method of inquiry: National Mortality Followback Survey pretest, 1986

Type of response	Method of inquiry ¹					
	Total	Mail	Telephone or personal visit	Total	Mail	Telephone or personal visit
	Number			Percent distribution		
All inquiries ²	1,360	1,360	512	100.0	100.0	100.0
Completed ³	1,184	796	388	87.1	58.5	75.8
Refused	60	31	29	4.4	2.3	5.7
Other nonresponse ⁴	116	533	95	8.5	39.2	18.6

¹Final method of inquiry attempted, not the initially assigned method.

²Includes inquiry to staff persons in facilities where a decedent died, for 25 decedents who were identified as having no living next of kin.

³Includes completed and fail-edit returns that provided some positive response.

⁴Cases of nonresponse by mail were assigned to telephone or personal visit followup. Therefore, these cases are duplicated in the mail and telephone or personal visit columns, and the columns do not add across. The total columns represent the net outcome after the field followup attempts.

NOTE: Percents may not add to totals due to rounding.

Table M. Number and percent distribution of cases assigned to the field by final response status and final method used, according to method of followup, for Illinois and Virginia: National Mortality Followback Survey pretest, 1986

<i>Final response status and final method used</i>	<i>Method of followup</i>					
	<i>Both methods</i>		<i>Telephone</i>		<i>Personal visit</i>	
	<i>Number</i>	<i>Percent distribution</i>	<i>Number</i>	<i>Percent distribution</i>	<i>Number</i>	<i>Percent distribution</i>
Cases assigned	448	100.0	241	100.0	207	100.0
<i>Positive responses</i>						
Total	341	76.1	185	76.8	156	75.4
Telephone.	209	46.7	182	75.5	27	13.0
Personal visit	132	29.5	3	1.2	129	62.3
<i>Refusals</i>						
Total	6	1.3	4	1.7	2	1.0
Telephone.	5	1.1	4	1.7	1	0.5
Personal visit	1	0.2	-	-	1	0.5
<i>Other noninterviews</i>						
Total	101	22.5	52	21.6	49	23.7
Telephone.	59	13.2	51	21.2	8	3.9
Personal visit	42	9.4	1	0.4	41	19.8

NOTE: Percents may not add to totals due to rounding.

Main survey methods and procedures

The results of the pilot study at the hospice, the minitest in the Washington, D.C., area, and the formal four-state pretest were carefully evaluated in designing the questionnaire and the procedures for the main survey for 1986. Consultations were held with the cosponsors, and the National Center for Health Statistics (NCHS) Work Group and the interagency Consulting Group expressed their views.

Questionnaire design

Two basic questionnaires were used in the 1986 National Mortality Followback Survey (NMFS): the informant questionnaire (NMF-1; see appendix) and the facility abstract record (NMF-6). The final informant questionnaire requested information on the four major topics described in "Selecting the foci of the 1986 NMFS." The basic informant questionnaire used for the mailing was modified for two other uses: a form adapted for the telephone and personal interview (NMF-4) and a shortened form for use when no relative of the decedent could be located and a telephone interview was conducted with a staff person in a nursing home (NMF-5).

A Facility Abstract Record (NMF-6) was used to collect information on the use of health care facilities in which the decedent spent at least one night during the last year of life. Identification of facilities used by the decedent came from the death certificate, from inquiry to the informants, and through inquiry about other relevant facilities from each facility contacted. A letter requesting information was sent to the administrator (NMF-61[L]) and to the medical record librarian of each facility (NMF-60[L]), and a Facility Abstract Record (FAR) was sent to the record librarian (NMF-6). The American Medical Record Association endorsed the survey, and a copy of this letter (NMF-62[L]) was sent to the medical record specialists. The FAR sought information on the following topics:

- The dates of each admission and discharge following January 1, 1985, a date specified to assure reports during the last year of life
- The diagnoses for each discharge
- The medical procedures administered
- Information on other facilities used by the decedent

In each case where the informant had completed the Authorization to Obtain Information from Medical

Records, a copy of this form was sent to the facility with the inquiry. This completed form was available for 75.5 percent of the survey records.

Details on the facility survey procedure are found under "Data processing."

Sample design

The 1986 NMFS was a national probability sample of all deaths of residents of the United States 25 years of age and over, occurring in the United States, except Oregon, in the year 1986. The sampling frame was the Current Mortality Sample (CMS), with a sample of death certificates drawn each month of the year (See description of the CMS under "Data processing"). Oversampling of selected groups was done to assure adequate analytic capability, especially for issues of concern to participating agencies. The CMS certificates drawn with certainty were: all death certificates for deaths from Ischemic heart disease in males 25-44 years of age and in females 25-54 years of age; all deaths due to Asthma; all deaths from specified cancer sites according to selected race/sex/age classes; and all deaths of American Indians, Aleuts, and Eskimos (table B). To fulfill these analytic needs, 2,274 death certificates were selected. In addition, black decedents were oversampled 2.9 times the rate for decedents who were not black, and decedents under 55 years of age were oversampled 3.1 times the rate of older decedents. The total survey sought information on 18,733 deaths in 1986.

Sources of information

The death certificates in the Current Mortality Sample file provided the initial source of information. Demographic data included date of death, age at death, date of birth, sex, race, marital status, usual residence, usual occupation and kind of business or industry, and service in the Armed Forces. These certificates also provided information on the cause of death, the place of death, the name and address of the informant, and the name of a surviving spouse.

After the data gathering was completed, the final file of information from death certificates, referred to as the Multiple Cause of Death File, was accessed, and pertinent data entered onto the survey data tape. Thus the final

recorded cause of death could be examined in relation to the survey data.

The informant (generally the decedent's next of kin) provided the basic survey data on the informant questionnaire. If the person to whom the questionnaire was mailed was unable to furnish the information sought, a request was included to identify a person who might know more about the decedent, and a questionnaire was mailed to that individual. However, only one questionnaire response for each decedent was used even if more than one was returned. The most complete response was accepted.

If no next of kin could be identified and the death certificate revealed a death in a nursing home, an interviewer telephoned the nursing home, and attempted an interview with a staff person who had known the decedent. An abbreviated Staff Questionnaire was used for these interviews. (NMF-5; see appendix). Staff Questionnaire interviews for 245 decedents (1.3 percent of the total sample) were attempted, and all were completed.

Information was also sought from all health care facilities used on at least an overnight basis by the decedent in the last year of life. These facilities, including hospitals, nursing homes, hospices, and other health care resources, were identified from the death certificates, reports by the informants, and reports by other facilities used by the decedents.

Collection of survey data

The U.S. Bureau of the Census served as the data collection agent for NCHS, both in the pretest and in the main survey. Questionnaires were mailed on a quarterly basis. All the forms used are listed in this report (See appendix III).

Informant survey

The informant data collection procedure consisted of the following steps:

1. Approximately 6 months after the death, a 24-page informant questionnaire—with a cover letter from the Director of NCHS and brief instructions for completing the form—was mailed by government-paid mail to the person named on the death certificate as the informant (NMF-1; see appendix). When no informant could be identified, the questionnaire was mailed to "Next of Kin" of the named decedent at the decedent's usual residence. A postage-paid return envelope was included. A reply within 5 days was requested.
2. Ten days after the first mailing, letters were sent to informants thanking them if they had returned the questionnaire and requesting that they do so if they had not yet completed the form (NMF-30[L]).
3. In cases where it appeared that families might have moved or broken up following a death, the post office

was requested to furnish a forwarding address for the informant, and a questionnaire was sent to the new address. When an addressee could not be located in this way, efforts were made through telephone directories, city directories, and other means to locate the informant.

4. About 4 weeks after the initial mailing, an identical questionnaire form and a revised cover letter were mailed to nonrespondents using first-class government-paid mail (NMF-2).
5. About 1 month after the second mailing, field interviews were attempted for those not responding to the two mailings. A telephone interview was the primary mode for field followup. If this effort failed, a personal visit to the home was made if the informant lived within 50 miles of the interviewer's residence (NMF-4).
6. For questionnaires returned, an edit check was made on 21 key items identified by the survey staff. If three or more of these key items failed the edit check, the case was referred to the field for telephone followup to complete these items and the entire questionnaire. (See "Clerical processing of the informant questionnaire.")
7. If a refusal was received from a spouse or a person residing at the decedent's address, either by mail or in the telephone or personal inquiry, no further effort to secure information was made, and the record was coded as a refusal. However, if another informant was interviewed and that person refused, inquiry was made as to whether some other family member or other person might be contacted.
8. For a sample of the responses that passed the edit check, a reinterview by telephone was conducted at least 2 weeks after the original response or interview. In the reinterview, the same informant was asked a limited number of the questions on the original questionnaire.

Exceptions to these procedures, as noted below, were followed at the request of some States.

In Pennsylvania, no mailings were made in the first quarter of the survey because clearance arrangements had not yet been completed. In the second quarter of mailings, a special form was included that permitted the respondent to refuse (NMF-11Pa; see appendix). Because this form produced such a high rate of refusals, it was revised for use in the third and fourth quarters (see NMF-11R[Pa]). In the second quarter, no personal visits were permitted. In the third and fourth quarters personal visits were permitted if the respondent stated on the form that it was acceptable.

In Idaho a cover letter from the State Registrar was included in the first mailing.

Michigan requested a list of the sampled death certificates for comparison against their "active" file to see if there should be any substitutions.

Facility survey

For the facility phase of the survey, the following procedures were used:

1. A letter was sent to the administrator of each facility reported (NMF-61[L]), and a letter and questionnaire (NMF-60[L] and NMF-6) were sent to the Director of Medical Records of the facility. If the informant had completed a form authorizing contact with the facility, this form was enclosed, but if no form was completed, the Facility Abstract Record was mailed nevertheless. Exceptions to this procedure were followed at the request of Pennsylvania and Vermont, where no facility inquiry was made without a consent form. NCHS secured an endorsement letter from the

American Medical Record Association, and a copy of the letter was sent to the medical record librarian. The Indian Health Service sent a letter to all of their hospitals urging cooperation with the survey. The Department of the Army did the same.

2. Up to three phone calls were made to facilities that failed to respond or that had returned forms that failed the edit check.
3. In cases where the facility requested reimbursement of copying expenses, reimbursement of up to \$5.00 was made for each copy of a medical record. Few requests were made for reimbursement. A Census Bureau representative assisted in completion of the questionnaires in one hospital that had a limited staff.

Data processing

There were four primary sources of information on decedents in the 1986 National Mortality Followback Survey (NMFS): the Informant Questionnaires, the Current Mortality Sample (CMS) death certificates, the Multiple Cause of Death File, and the Facility Abstract Records (FAR). In addition to these four primary sources there was an important quality-control document, the Reinterview Questionnaire (NMF-8). All five of these sources for each decedent required clerical and computer processing as described in the sections below.

A CMS death certificate record was included for all 18,733 decedents in the 1986 NMFS. Data are available from the informant questionnaire for 16,598 decedents (88.6 percent) and from the Multiple Cause of Death File for 18,707 decedents (99.9 percent).

During data processing, data reported by one responding source was not changed because it was inconsistent with information from another source, since it was impossible to determine which source was correct. The decision to retain the inconsistent responses allows flexibility in the analyst's choice of data items and also permits certain methodological studies.

Missing data were not imputed in the informant questionnaires. The decision not to impute was made after lengthy consultation with data users. The majority opinion of data users was that imputation could potentially cause more errors than it could eradicate and that it was therefore preferable to leave the decision as to whether or not to impute and the method of imputation to the data analysts.

It is National Center for Health Statistics (NCHS) policy that public-use data tapes for elementary units (persons, events, and health facilities and services) be released in a manner that will not compromise the confidentiality guaranteed the respondents who supply the original data. The measures taken to protect confidential information on NMFS decedents and respondents follow the practices of NCHS. Personal names and addresses and certificate numbers of vital records do not appear on the public-use data tapes. In addition, because of the amount of information about each decedent obtained from the informant questionnaire, and the linking of multiple sources of data for each decedent, no geographic information below the State level is shown on the files.

Current Mortality Sample death certificates

The detailed specifications for the routine processing of the Current Mortality Sample (CMS) death certificates are outlined elsewhere (14). Briefly, the CMS included death certificate record information for all 50 States, plus New York City and Washington, D.C. The registration areas were requested to submit copies of a 10-percent sample of their regular death file for the CMS by the end of the month following the month in which they receive the certificates. Key-to-disc processing was the primary mode of data entry; data were keyed directly into a minicomputer. Interactive with key entry, the computer software performed valid code field edits and selected interfield dependency edits where applicable. The results of the edits were displayed on a screen for immediate resolution by the key entry operator or referral to the supervisor, if necessary. There was a consistency edit among age, sex, and cause-of-death code assignment. The key entry of each CMS record was 100-percent verified through an independent key verification process.

To facilitate administrative control of the 1986 NMFS sample file by the Census Bureau, NCHS selected the sample records and prepared a master file tape containing, for each record, the death certificate number, a unique control number, the name of the decedent, and the name and address of the informant. In addition, two photocopies of the death certificate were sent to the Census Bureau. This process continued until June 1987 in order to obtain virtually all certificates for 1986 deaths that were filed late into 1987.

At a later date, the full CMS file was accessed to obtain data for each NMFS decedent including age, sex, race, and underlying cause of death. This information was merged with the above-described file.

Because the industry and occupation items were not contained on the CMS file, these items from the death certificates were coded by Census Bureau coders based on the "1983 Procedures Manual for Industry and Occupation Coding for Death Certificates" (15). This file was later merged with the other CMS information on the decedent.

The Multiple Cause of Death File

The Multiple Cause of Death File contains information from the death certificate on all deaths occurring in the 50 States, the District of Columbia, Puerto Rico, the Virgin Islands, Guam, American Samoa, and the Trust Territory of the Pacific Islands. Whereas the CMS file only contains the underlying cause of death—defined as “(a) the disease or injury which initiated the train of events leading directly to death, or (b) the circumstances of the accident or violence which produced the fatal injury” (16)—the Multiple Cause of Death File contains codes for all medical conditions that are reported on the death certificate regardless of whether the condition contributed to death. The Multiple Cause of Death File is considered more complete and accurate than the CMS because in some cases a death certificate is amended after the CMS record is filed.

All States and the District of Columbia provided NCHS with the demographic parts of the death certificate already coded on magnetic tape. Twenty-two States provided cause-of-death coding on computer tapes according to NCHS specifications. NCHS keyed the medical information for the balance of the areas. As with demographic data, mortality medical data were also subject to quality control procedures against errors of both coding and data entry. (The detailed processing specifications can be found in publications listed in references 17–19.)

The Multiple Cause of Death File information for the sampled decedents was merged with the other decedent information from the CMS and the informant questionnaire. Twenty-six records (0.1 percent) have no matching Multiple Cause of Death File information.

Informant Questionnaire

The information from all informant questionnaire forms (NMF-1, NMF-2, NMF-4, and NMF-5) was processed by the U.S. Bureau of the Census as described below.

Clerical processing of the informant questionnaire

Upon receipt of a mailed questionnaire, an edit was performed on 21 key questionnaire items. If three or more of these key items were blank or illegible, a telephone followup was made. In the telephone followup, the interviewer went through the entire questionnaire (not just the 21 items) to make necessary additions and corrections.

The questionnaires were further hand coded to prepare the form for data keying (for example, converting written entries to numeric equivalents, reducing ranges and fractions to whole numbers, etc.). Detailed editing and coding instructions were given for specific question items such as reclassifying or recoding “other” entries based on NCHS specifications.

In addition, facilities where decedents stayed during the last year of life were identified from the completed

questionnaires and corresponding death certificate during the clerical processing, and Decedent Control Forms (NMF-6A) and Facility Control Forms (NMF-6B) were completed. (See section below.)

Before data keying, the first 100 edited and coded questionnaires each quarter were sent to NCHS for review. Revisions and clarifications were made to some editing instructions to account for situations that were not anticipated.

A “source code” method was used in data keying: each response item on the questionnaires had a unique source code. Identical response items across questionnaire types had identical source codes. If a response item was blank, nothing was keyed for the source code. The level of detail on the questionnaire was retained during keying (in other words, no response codes were grouped during keying, which would have resulted in a loss of detail).

Computer processing of the informant questionnaire

A “pre-edit” was performed that involved matching the informant file to the master file containing the case management information on each sample case. Inconsistencies, such as duplicates, mismatched data file and master file records, and out-of-sequence source codes, were rejected and manually inspected. The majority of the rejects were duplicate records. The second most common reject involved missing records, most of which were late receipts that had not been “check-in keyed.” Corrected rejects were recycled and verified.

After pre-editing, the following edits and reformatting were completed:

- File formatting—The questionnaires were keyed by source code. The keyed file was reformatted to contain only fixed-length fields. Each reformatted data file record was then appended to the corresponding master file record.
- Item reformatting—Certain items, such as multiple entry items, required reformatting.
- Range checks—These checks identified valid and out-of-range entries for each item. A “Not Ascertainable” (NA) code was used for each blank or out-of-range entry.
- Consistency edit—These edits were performed to ensure that responses to specific items in the questionnaire were consistent or equivalent to other items in the questionnaire. These were a “forward” type of edit, in that if a subsequent item was inconsistent with a previous entry, the previous entry was retained and the subsequent entry was changed to an NA code. For example, if the response to the question “During his or her entire life, was the person ever admitted to a nursing home?” was “No” and the entry for the subsequent question “What was the total amount of time the person spent in a nursing home over his or her entire lifetime?” was “Less than 3 months,” the response to the latter question was changed to an

out-of-universe code. However, if a previous entry was blank and reasonable data followed, the previous blank was changed to a "Yes" or "No" to be consistent. For example, if the response to the question "During his or her entire life, was the person ever admitted to a nursing home?" was blank, and the entry for the subsequent question "What was the total amount of time..." was "Less than 3 months," the entry for the previous question was changed to "Yes."

- Blanking edit—Fields not requiring entries were blanked out, so that the universe for each item was well defined. Each blanked field was filled with "9," "99," "999," and so forth to indicate to the file user that the item was out of universe.

Finally, certain data items such as age, industry and occupation, and payment sources for health care were recoded to assist data users. The original codes were also retained for all recoded items.

A review of item counts called the "universe verification," was performed after processing each quarter of data to verify that the above edits were properly applied to the file.

The informant questionnaire file was merged with the CMS file and the file containing the industry and occupation codings from the death certificates prior to sending the file to NCHS.

Decedent Control Record (NMF-6A)

The facilities used by a decedent during the last year of life were identified from the informant questionnaire, from the death certificate, and from facilities themselves. A Facility Control Record (NMF-6B) was completed for each facility identified. A Decedent Control Record (NMF-6A) was completed for each decedent using a facility. The Facility Control Record listed all decedents identified as using that facility and the facility's name, address, and telephone number. The Decedent Control Record listed all facilities used by that decedent and the facility control numbers. Keying the Decedent Control Record information created a file which was merged with the informant questionnaire information. The merging process also involved editing the final status codes for the Decedent Control Records, correcting inconsistencies between the informant questionnaire final status code and the Decedent Control Record, and eliminating duplicate Decedent Control Records.

Facility Abstract Records (FAR)

The FAR's were reviewed by the NCHS Data Processing Branch for problems prior to data keying. In

addition, data from facilities that sent medical record facsimiles rather than completed FAR's were transferred to the FAR prior to data entry. In the review of the FAR's, dates and the final status codes were checked for consistency.

In keying a FAR, the data keyer first entered the decedent's control number. The data entry computer program brought up a reference file consisting of the decedent's control number, date of death, date of birth, age, and sex. This information was used as the first part of the FAR record.

The quality control procedure for data entry consisted of drawing a 5-percent sample and performing an independent verification. The data entry supervisor and senior data entry personnel adjudicated any differences and tallied errors. The quality control procedure for the transfer of facsimile information to the FAR was a dependent verification conducted manually by the data entry supervisor and senior data entry personnel. For each keyer, the first 50 FAR's for which transfers were made were 100-percent verified. After the error rate was determined to be minimal, this verification was reduced to 5 percent.

As part of the data entry program there were computer edits that included consistency checks on dates, age, sex, medical condition, and procedure codes. Inconsistencies were resolved during the data keying by the data keyer in consultation with the keying supervisor.

Reinterview questionnaire

The clerical processing and computer processing of the reinterview questionnaires (NMF-8) were similar to those of the informant questionnaire except that there was no key item edit. A pre-edit was performed on the reinterview status item. The code range checks, consistency checks, etc. were identical to those for the informant questionnaire for those items contained on the reinterview. The reinterview information is not contained on the public-use data tapes but is summarized and presented in the section "Nonsampling error."

Final preparation of the public-use data tapes

In the final preparation of the public-use data tapes, confidential information was removed (as described above), the file was reformatted, and weights were entered on the file. For a discussion of the weights, see "Estimation."

Estimation

National Mortality Followback Survey (NMFS) data must be weighted in order to prepare nationally representative estimates. Unweighted NMFS data usually cannot be used for analysis because use of unweighted estimates ignores the NMFS disproportionate sampling. Probability sampling allows the NMFS data to be weighted to produce national estimates for the United States, excluding Oregon. It also allows approximation of the sampling errors.

The NMFS weights were prepared by a poststratified ratio estimation procedure (table N). The weight for each sample decedent is based on a product of three component weights:

- *Probability of selection*—The basic weight for each sample decedent is the reciprocal of the probability of sample selection.
- *Adjustment for nonresponse*—To reduce nonresponse bias, the NMFS sampling weights are adjusted for informant nonresponse. This adjustment was implemented within subsets of the sampling strata and was the reciprocal of the response rate within the subset. This adjustment reduces nonresponse bias to the extent that informant data for a nonrespondent is similar to data for respondents in these adjustment classes.
- *Poststratification by age, sex, and race*—Within 28 post-strata defined by decedent age, sex, and race (table N), the NMFS estimates were ratio-adjusted to counts for the number of deaths reported to the

National Center for Health Statistics (NCHS) for the United States, excluding Oregon. This adjustment makes the weighted sample more representative of the target population by age, sex, and race.

An important issue in estimation is that the NMFS represents the universe of resident deaths in 1986 among adults 25 years of age and over (excluding Oregon). It therefore cannot be used to calculate probabilities of death unless a population base (the denominator) is obtained. There are several possible sources of denominator data: the 1986 Current Population Survey (CPS), conducted by the Bureau of the Census; the National Health Interview Survey (NHIS), conducted by NCHS; and the 1985 National Nursing Home Survey (NNHS), conducted by NCHS. None of these sources corresponds exactly with the NMFS. For example, the NHIS covers the civilian noninstitutionalized population, as opposed to the coverage of the whole population by the NMFS. However, persons may be classified as institutionalized or not in the NMFS. For this purpose it is recommended that source code 051 be used, with a code of 2 or 3 indicating that the person was institutionalized for half or more of 1986. In addition, the civilian status of decedents may be determined from source code 146. For use as denominator data with the 1986 NMFS, the 1986 NHIS included supplemental items on longest occupation and industry.

Table N. Weighting and sampling strata definitions, by reciprocal of the probability of sample selection, age group, number of cases in survey, and response rate: National Mortality Followback Survey, 1986

<i>Weighting stratum</i>	<i>Sampling stratum</i>	<i>Reciprocal of the probability of selection</i>	<i>Age</i>	<i>Number of cases in survey</i>	<i>Response rate per 100 cases</i>
11	1. All causes, American Indian, Eskimo, and Aleut	10.00	25-34 years	55	87.27
12	1. All causes, American Indian, Eskimo, and Aleut	10.00	35-44 years	63	88.89
13	1. All causes, American Indian, Eskimo, and Aleut	10.00	45-54 years	80	85.00
14	1. All causes, American Indian, Eskimo, and Aleut	10.00	55-64 years	77	93.51
15	1. All causes, American Indian, Eskimo, and Aleut	10.00	65-74 years	85	91.76
16	1. All causes, American Indian, Eskimo, and Aleut	10.00	75-84 years	112	91.07
17	1. All causes, American Indian, Eskimo, and Aleut	10.00	85 years and over	68	97.06
21	2. Specified heart disease, black	10.00	25-44 years	147	88.44
22	2. Specified heart disease, other than black	10.00	25-34 years	76	86.84
23	2. Specified heart disease, other than black	10.00	35-44 years	603	89.05
24	2. Specified heart disease, black	10.00	45-54 years	94	88.30
25	2. Specified heart disease, other than black	10.00	45-54 years	349	86.25
31	3. Specified asthma, black	10.00	25 years and over	61	90.16
32	3. Specified asthma, other than black	10.00	25-64 years	77	89.61
33	3. Specified asthma, other than black	10.00	65 years and over	182	92.86
41	4. Specified cancer, all races except American Indian, Eskimo, and Aleut	10.00	25 years and over	145	91.72
51	5. Not external causes, black	32.45	25-34 years	209	84.21
52	5. External causes, black	32.45	25-34 years	188	84.57
61	6. Not external causes, black	36.78	35-44 years	283	84.48
62	6. External causes, black	36.78	35-44 years	99	84.85
71	7. All causes, black	52.86	45-54 years	405	84.44
81	8. All causes, black	52.86	55-64 years	767	88.66
91	9. All causes, black	52.86	65-74 years	1,013	88.90
100	10. All causes, black	52.86	75-84 years	940	91.70
110	11. All causes, black	52.86	85 years and over	543	92.63
121	12. Not external causes, other than black	32.45	25-34 years	532	84.59
122	12. External causes, other than black	32.45	25-34 years	702	82.91
131	13. Not external causes, other than black	36.78	35-44 years	868	85.37
132	13. External causes, other than black	36.78	35-44 years	412	81.31
141	14. Not external causes, other than black	79.08	45-54 years	941	87.67
142	14. External causes, other than black	79.08	45-54 years	147	80.27
151	15. Not external causes, other than black	185.12	55-64 years	1,208	89.07
152	15. External causes, other than black	185.12	55-64 years	50	80.00
161	16. Not external causes, other than black	185.12	65-74 years	2,205	88.39
162	16. External causes, other than black	185.12	65-74 years	65	87.69
171	17. Not external causes, other than black	185.12	75-84 years	2,703	90.12
172	17. External causes, other than black	185.12	75-84 years	58	94.83
180	18. All causes, other than black	185.12	85 years and over	2,116	92.20

NOTES: A certificate was assigned to the first stratum for which it was eligible. A certificate was classified as an external cause of death if the cause was coded E800-E999, according to ICD-9 (World Health Organization, Manual of the International Statistical Classification of Diseases, Injuries, and Causes of Death, based on the recommendations of the Ninth Revision Conference, 1975. Geneva: World Health Organization, 1977). Each weighting stratum is a subset of a sampling stratum.

Sampling error

Because the National Mortality Followback Survey (NMFS) estimates are based on a sample, the estimates may differ from figures that would have been obtained in a survey of all death certificates for decedents in 1986 who were 25 years of age and over, using the same data collection instruments and procedures. Probability sampling in the NMFS allows approximation of the sampling error.

The standard error of an estimate is primarily a measure of the variability that occurs by chance (the sampling error) because a sample of the population rather than the total population is surveyed. Although the standard errors calculated for the NMFS estimates reflect some of the random variation inherent in the measurement process, they do not measure any systematic error. The relative standard error (RSE) of an estimate is obtained by dividing the standard error of the estimate by the estimate itself and is sometimes expressed as a percent.

In repeated samples using the same questionnaires and procedures, the chances are about 68 in 100 that an estimate from the sample differs by less than one standard error from the corresponding figure that would be obtained through a survey of all death certificates for decedents 25 years of age and over. The chances are about 95 in 100 that an estimate from the sample differs by less than two standard errors from the figure that would be obtained through a survey of all death certificates for decedents 25 years of age and over.

The standard error of a statistic depends not only on the sampling design but also on the statistic itself; the standard error is higher for measurements that are highly variable from one sample unit to another and lower for measurements that are less variable. Because the standard errors for survey statistics are estimated from sample data, they are themselves subject to sampling error, which may be large in some cases.

Estimation of standard error

The standard errors for the NMFS were estimated by a balanced-repeated-replication procedure using 20 replicate half samples. This procedure estimates the standard errors for survey estimates through the observation of the variability of estimates based on replicate half samples of

the total sample. This estimation procedure was developed and described by McCarthy (20,21).

Standard error approximation

The balanced-repeated-replication procedure can be used to calculate directly the standard error and the relative standard error for all estimates from the NMFS. However, this procedure is not practical or feasible for all users of these data. The balanced-repeated-replication procedure was therefore used to develop a generalized procedure for approximating the relative standard errors for NMFS estimates.

Relative standard errors were calculated using the balanced-repeated-replication procedure for several thousand estimates from the overall NMFS analysis plans. Samples of 100 NMFS aggregate estimates were selected from domains defined by the decedent's race, age, and sex. Each sample was then used to calculate the parameters for the formula:

$$RSE(x) = \sqrt{A + (B/x)}$$

Eighteen pairs of A and B parameters for this formula were adequate to approximate the relative standard error for aggregate NMFS estimates (table O). The standard error of an estimate can be obtained by multiplying the relative standard error of the estimate by the estimate itself.

Standard error applications

Standard error for aggregate estimates—The approximate standard error of an estimated number of decedents with a particular characteristic, x , is calculated by

$$RSE(x) = \sqrt{A + (B/x)}$$

$$\text{and } SE(x) = x \cdot RSE(x)$$

where x = estimated number of decedents
 A, B = parameters from table O
 $RSE(x)$ = relative standard error of x
 $SE(x)$ = standard error of x

These formulas are not appropriate for estimates of the total number of decedents in a poststratification cell or

Table O. Parameters used to approximate the relative standard errors for estimates of decedents, by race and age: National Mortality Followback Survey, 1986

Race and age	Parameters	
	A	B
All races		
Total	-0.000088	173.472799
25-34 years.	-0.000725	40.250787
35-54 years.	-0.000306	57.187500
55-69 years.	-0.000325	189.139047
70-84 years.	-0.000219	200.749692
85 years and over.	-0.000430	181.208646
Black		
Total	-0.000250	57.315899
25-34 years.	-0.002721	36.923295
35-54 years.	-0.001278	48.883512
55-69 years.	-0.000863	64.860422
70-84 years.	-0.000688	59.820841
85 years and over.	-0.001911	54.630073
All other races		
Total	-0.000106	184.663690
25-34 years.	-0.000948	39.640859
35-54 years.	-0.000419	62.024668
55-69 years.	-0.000411	214.015461
70-84 years.	-0.000253	211.433987
85 years and over.	-0.000484	190.261795

NOTE: The sample consisted of 18,733 decedents; completed questionnaires were obtained for 16,598 persons.

in a combination of such cells, because these estimates have negligible error. Since each poststratum total of the number of death certificates for decedents who were not black is dominated by the number of death certificates for white decedents, consider the number of death certificates for white decedents in one or more other-than-black postrata as being subject to negligible error.

Example: Based on the NMFS, it is estimated that 254,540 decedents 70-84 years of age had been admitted to a nursing home.

The standard error of this estimate is calculated as follows:

$$\begin{aligned} \text{RSE}(254,540) &= \sqrt{-0.000219 + (200.749692 / 254,540)} \\ &= 0.024 \end{aligned}$$

$$\text{and SE}(254,540) = 254,540 \cdot 0.024 = 6,109$$

Standard error for ratio or proportions where the denominator is assumed to have negligible error—Where the denominator of a ratio is the estimated total number of deaths in a poststratification cell or in a combination of such cells, the relative standard error of the ratio is the relative standard error of the numerator. Thus, the approximate standard errors may be calculated using the formulas

$$\text{RSE}(r) = \text{RSE}(x/y) = \text{RSE}(x)$$

$$\text{and SE}(r) = r \cdot \text{RSE}(x)$$

where r = ratio or proportion

x = numerator of the ratio

y = denominator of the ratio with negligible error

$\text{RSE}(r)$ = relative standard error of r

$\text{SE}(r)$ = standard error of r

$\text{RSE}(x)$ = relative standard error of x

Example: An estimated 30.4 percent (254,540) of decedents 70-84 years of age (836,443) had ever been admitted to a nursing home. The number of decedents 70-84 years of age is a combination of the poststratification cells specified in table N. Therefore,

$$\begin{aligned} \text{RSE}(30.4) &= \text{RSE}(254,540 / 836,443) \\ &= \text{RSE}(254,540) \\ &= 0.024 \text{ (from the prior example)} \\ \text{SE}(30.4) &= 30.4 \cdot 0.024 = 0.7 \end{aligned}$$

Standard errors for percentage estimates where both the numerator and the denominator are subject to sampling error—The formulas used to approximate the standard error for a percentage estimate where both the numerator and the denominator are subject to sampling error are:

$$\text{RSE}(p) = \text{RSE}(100x/y) = \sqrt{(B/p) \cdot (100-p)/y}$$

$$\text{and SE}(p) = p \cdot \text{RSE}(p)$$

where B = parameter from table O
 p = $100 \cdot x/y$, the estimated percentage,
 x = estimated number of deaths in the numerator of the percentage
 y = estimated number of deaths in the denominator of the percentage

$\text{RSE}(p)$ = relative standard error of p

$\text{SE}(p)$ = standard error of p

Example: An estimated 80.7 percent of all decedents who ever smoked (1,088,094) smoked for 10 years or more.

$$\text{RSE}(80.7) = \sqrt{(173.472799 / 80.7) \cdot (100-80.7) / 1,088,094} = 0.006$$

$$\text{and SE}(80.7) = 80.7 \cdot 0.006 = 0.5$$

This approximation of the absolute or relative standard error of a percentage is valid if either the relative standard error of the denominator is less than 5 percent (22), the relative standard errors of the numerator and the denominator are both less than 10 percent (23), or both.

Standard error for ratios ($r = x/y$) where the numerator is not a subclass of the denominator—The standard error of a ratio may be approximated as

$$\text{RSE}(r) = \text{RSE}(x/y) = \sqrt{\text{RSE}^2(x) + \text{RSE}^2(y)}$$

$$\text{and SE}(r) = r \cdot \text{RSE}(r)$$

where x = numerator of the ratio
 y = denominator of the ratio

$\text{RSE}(r)$ = relative standard error of the ratio r

$\text{SE}(r)$ = standard error of the ratio r

RSE(x) = relative standard error of the numerator x

RSE(y) = relative standard error of the denominator y

This approximation of the absolute or relative standard error of a ratio is valid if either the relative standard error of the denominator is less than 5 percent (22), the relative standard errors of the numerator and the denominator are both less than 10 percent (23), or both.

Testing differences in the National Mortality Followback Survey (NMFS)

The standard error of a difference between two statistics is approximately the square root of the sum of the squares of the standard errors of the individual statistics. This formulation of the standard error of the difference of two statistics quite accurately approximates the standard error for the difference between uncorrelated statistics; however, it only roughly approximates the standard error in most other cases.

Although the exact number of degrees of freedom in the NMFS sampling variances is not known, the number

of degrees of freedom may be approximated by the number of pseudo strata used in the balanced-repeated-replication procedure. Accordingly, hypotheses about differences between estimates are tested using 20 degrees of freedom for the 1- or 2-tailed *t*-test as appropriate.

Example: 12.0 percent of the 878,281 decedents who smoked for 10 years or more died of Malignant neoplasms of respiratory and intrathoracic organs, and 1.2 percent of the 827,899 decedents who never smoked died of Malignant neoplasms of respiratory and intrathoracic organs.

To test whether this difference is significant at the 0.05 level, compute

$$\begin{aligned} t &= \frac{12.0 - 1.2}{\sqrt{(12.0 \cdot \text{RSE}(12.0))^2 + (1.2 \cdot \text{RSE}(1.2))^2}} \\ &= \frac{10.8}{\sqrt{(12.0 \cdot 0.038)^2 + (1.2 \cdot 0.131)^2}} \\ &= 22.4 \end{aligned}$$

The 2-tailed 0.05 critical value for a *t*-statistic with 20 degrees of freedom is 2.086. Accordingly, the difference is significant at the 0.05 level.

Nonsampling error

Estimates based on the 1986 National Mortality Followback Survey (NMFS) are subject to nonsampling as well as sampling error. Sources of nonsampling error include incomplete coverage, ambiguity in the wording of questions, incomplete or inaccurate responses, and errors in data reduction and processing. Although the extent of such nonsampling errors was generally not measured, the survey procedures in the NMFS were designed to minimize the introduction of such error.

Undercount of deaths is considered negligible; it is believed that more than 99 percent of the deaths occurring in the United States are registered. A number of studies of quality of medical certification on the death certificate have been done. In general, these have been for relatively small samples and for small geographic areas, for example, a city or a State. A bibliography, prepared by the National Center for Health Statistics (NCHS) (24), covering 128 references over a period of 23 years, indicates that no definitive conclusions have been reached about the quality of medical certification on the death certificate. There is no well-defined program for systematic assessment of the quality of medical certifications reported on death certificates or for measuring the error effects on the levels and trends of cause of death statistics in the United States.

One index of the quality of reporting causes of death is the proportion of death certificates coded as "Symptoms, signs, and ill-defined conditions" (ICD-9 Code 780-799, Ninth Revision). Although there are cases for which it is not possible to determine the cause of death, this proportion indicates the care and consideration given to the certification by the medical certifier. It may also be used as a rough measure of the specificity of the medical diagnoses made by the certifier in various areas. In 1986, 1.5 percent of all reported deaths in the United States were assigned to ill-defined or unknown causes. However, this percentage varied among the States, from 0.3 percent to 4.0 percent (25).

The coding error rate in 1986 for the medical information on the death record was just above 4 percent for the 22 States processing this information and about 3 percent for the areas processed by NCHS. The estimated average error rate for all demographic items in 1986 was 0.25 percent (25).

As for the Current Mortality Sample (CMS), complete information concerning the cause of death is

sometimes not available in the State offices when the sample is drawn but is available later when copies of the final death certificates are processed. As a result, estimates based on sample counts for certain causes are biased estimates of final counts. A more complete discussion of these biases can be found in the publication listed in reference 26.

Data errors may have been introduced in the survey if the respondent was unwilling or unable to respond. To avoid problems such as ambiguous or unclear wording of an instruction, question, or response category, NCHS staff thoroughly pretested the NMFS questionnaires. Questions with high "Don't know" rates and high gross error rates (as measured by a pretest reinterview program conducted on 22 percent of the interviews) were not included in the main survey. (See "The formal pretest.") Furthermore, interviewers and supervisors underwent thorough training and only experienced Census Bureau interviewers were used.

Extensive efforts were made to find suitable respondents and to get interviews from them in an effort to minimize the nonresponse bias. As explained in "Collection of survey data," if a mail return was not received, telephone and personal attempts were made. If the interviewer could not reach the informant listed on the death certificate, attempts were made to secure another knowledgeable respondent. For decedents who had spent much or all of their last year living in a health care institution and for whom a knowledgeable relative was unattainable, a staff member at the institution was interviewed.

A very stringent clerical edit of mail returns was used to minimize errors arising from the difficulty some respondents had in completing the self-administered questionnaire. (See description in "Data processing.") This stringent edit resulted in a fail-edit rate of 10.2 percent. Of those questionnaires failing edit, 86.2 percent were followed up by telephone. The interviewer went through the entire questionnaire resolving missing information and inconsistencies. The main reason that 13.8 percent of the fail-edits were not followed up was that there was no telephone, and cost considerations prevented personal visits.

The reinterview served the purpose of providing a measure of the simple response variance component of the survey error for those items included on the

reinterview. It also ensured that an interview had actually taken place for those cases in which an interviewer had filled in the questionnaire. (See "Reinterview.")

The quality control during data processing as described in the section on "Data processing" was very stringent in order to minimize error in the data. Data keypunching for the informant questionnaire was 100-percent verified. There was extensive clerical and computer editing of documents.

The purpose of the weighting was to reduce further the error in the data. Selection weights were used to adjust

for unequal probability of selection for the survey. Adjustment for nonresponse was made to correct for differential rates of response. Poststratification weights were applied to compensate for coverage gaps and to ensure the consistency between population counts and the NMFS estimates for primary domains of study.

In summary, extensive efforts were made in every aspect of survey planning, design, data collection, and data processing to minimize potential nonsampling errors.

Reinterview

A reinterview was conducted with the original respondent 2 or more weeks following the original completion of the questionnaire for a sample of the returns with a complete or partial complete status and, in the case of the mailed questionnaires, only for those that passed the key item edit check. The reinterview questionnaire (NMF-8) contained a subset of 32 response items from the original form. Five percent of all decedents were identified as possible candidates for inclusion in the reinterview. Cases were selected according to the last two digits of the control number. Cases for which a complete or partial original interview status was not obtained, those that failed the key item edit or that used the staff questionnaires (NMF-5), and those where informants had no telephone were excluded from the reinterview.

The "No phone," "Informant deceased," and "Informant incapable" cases were considered out of scope. The total response rate for the reinterview was 77 percent. Administrative problems were primarily responsible for the lower reinterview response rate. There were 507 reinterviews with a status of partial or complete, resulting in a partial or complete reinterview for 3.1 percent of the original 16,598 responses with a status of partial or complete. Of the 507 reinterviews, 480 (94.7 percent) had a complete reinterview status. Of these same 507 reinterviews, 405 (79.9 percent) were originally completed by mail, 44 (8.7 percent) had a personal original interview, and 152 (30.0 percent) had a telephone original interview, and for 6 cases (1.2 percent) the type of original interview was not ascertained.

The reinterview process provides a measure of the reliability of the survey items. The simple response variance contribution to the total survey error may be calculated by comparing the original interview responses to the responses to the same questions asked in the reinterview (27). The simple response variance, also called the "gross error rate," is calculated by dividing the number of cases in which reinterview response differs from the original response by the total number of reinterview cases. Table P contains the gross error rates for the items contained on the reinterview.

Items were selected to be on the reinterview for one of four reasons. A few items, such as marital status, were included because of their analytical value and likelihood of being reported with the highest level of accuracy. A few items were included in the reinterview because they were

Table P. Gross error rates of items included in the reinterview: National Mortality Followback Survey, 1986

<i>Item and source code in questionnaire</i>	<i>Gross error rate</i>	
Ever had a stroke073	10.0
Age at first stroke ¹074	23.5
Cancer was main condition leading to death081	5.4
Time before death that cancer was first diagnosed ²082	20.3
Ever near death but lived on091	20.3
When near death but lived on092	27.4
Activities in hour before death095	
Confined to bed or chair		33.0
Working		8.5
Quiet recreation		13.1
Active recreation		8.5
Sleeping		22.7
Comatose		19.1
Eating		7.4
New or sharply increased problem in hour before death096	42.1
At least 12 drinks of alcohol in adult life129	14.7
Frequency of drinking130	41.5
Drinks per day131	50.5
Frequency of vigorous exercise132	27.8
Ever worked at a paying job or business133	5.0
Longest occupation ³		31.9
Longest industry ³		26.7
Marital status161	5.4
Number of different spouses164	6.7
Spouse (any) ever smoked166	78.6
Number of cigarettes a day, spouse167	54.7
Year of father's birth168	27.2
Father's age at death169	35.8
Father ever had heart attack172	21.1
Father's age at heart attack173	23.8
Number of brothers176	22.8
Number of brothers who had heart attacks177	20.3
Ages of brothers at heart attacks ⁴178-183	29.2

¹Responses were considered in agreement if ages differed by 5 years or fewer.

²Responses were considered in agreement if times differed by one year or less.

³Based on the recodes; refer to appendixes B, E, and F of Public-Use Data Tape Documentation (1990 National Ambulatory Medical Care Survey, Hyattsville, Maryland: National Center for Health Statistics, 1992).

⁴Responses were considered in agreement if ages or years differed by 10 years or fewer.

included in the survey after the pretest and were not tested. Some other items were included in the reinterview because either they underwent substantial change after the pretest or they presented problems in the pretest (for example, high "Don't know" rates). Finally, some items were included in the reinterview simply because they were necessary screener items (for example, it was necessary to

include the question on the number of different spouses in order to include the questions on the number of spouses who smoked and how much).

In general, rates below 10.0 percent may be considered low. Items with rates between 10.0 and 20.0 percent should be analyzed with caution, and items with rates above 20.0 percent should be analyzed with extreme caution. High rates may be an indication that improvements are needed in the methods used to collect these data, the concept itself may not be measurable, or respondents are not able to provide accurate information to the detail desired.

Items with low gross error rates included whether cancer was the main condition leading to death (5.4 percent), whether the decedent had ever worked at a job or business (5.0 percent), marital status (5.4 percent), and the number of different spouses (6.7 percent). The item used to determine whether the decedent had ever drunk alcoholic beverages had a somewhat higher error rate (14.7 percent). Among the items with high error rates were frequency of drinking alcoholic beverages (41.5 percent), number of drinks per day (50.5 percent), whether the decedent was sleeping at the time of death (22.7 percent), and whether the decedent's father ever had a heart attack (21.1 percent).

The type of response categories may affect the rate: items with more response categories usually will have

higher response error rates, in part because there is more room for error. It may be useful to compute the error rates with response categories grouped into a smaller number of responses and to use grouped responses in data analysis so that the effect of errors is lessened.

Several examples illustrate this point. The error rate for the item querying the time before death when the decedent was near death but lived on (source code 092) was 27.4 percent when four categories were used, but the error rate was 10.5 percent when the response categories were grouped into two categories: less than 1 year and 1 year or more. The error rate for the item on frequency of drinking alcoholic beverages (source code 130), was 41.5 percent when five categories were used, but when the categories were grouped into at least once a week and less than once a week, the error rate was 18.8 percent. The error rate for number of alcoholic drinks consumed was 50.5 percent for six detailed categories, but was 22.7 percent for the two grouped categories of "less than 5" and "5 or more." For the item on number of cigarettes the spouse smoked (source code 166), when the response categories are grouped into fewer than 25 and 25 or more, the error rate remained quite high at 34.3 percent. For the item on the time before death that cancer was first diagnosed, the error rate was 11.9 percent, when the responses were considered as not different if the time difference was 3 years or less.

Response characteristics

The responses received in the pretest were classified into the following categories:

- *Complete interview*—A questionnaire returned by mail or completed by telephone or personal interview, with essentially all of the items containing a response
- *Fail-edit*—A questionnaire returned by mail containing substantial responses but failing to pass the rigorous edit check (See “Data processing.”)
- *Partial interview*—A questionnaire completed in the field with substantial but incomplete responses
- *Refused*—A response by mail or field contact which specifically refused to provide information on the survey (See “Collection of survey data.”)
- *Cannot contact, outside primary sampling unit*—A referral to the field, with the informant residing more than 50 miles from the interviewer’s location
- *Cannot contact, other reason*—A referral to the field in which contact could not be made with the informant, for example, failure to reach by telephone, or not at home after repeated attempts for personal interview, etc.
- *Cannot locate*—A referral to the field with the informant not located
- *Other noninterview*—A referral to the field with no interview possible for other reasons
- *No informant identified*—Inability to mail the questionnaire because no informant could be identified, for example, if the informant was reported to have died, moved without a forwarding address, etc., and no other informant could be identified

The number and percent of responses received in the survey for each category of response are shown in table 1. In the following discussions the terms “response” or “completed” include complete interviews, fail-edit mail returns, and partial field interviews.

The death certificates included in the survey sample contain demographic and other characteristics of the decedents. Using these data as the universe of the sample, and hence as the denominator, it is possible to calculate response rates according to these characteristics of the decedent. It is important to observe, however, that no demographic information on the informants (respondents) was sought, so all response characteristics discussed here refer to those of the decedent.

Response from informants

The total survey response rate was 88.6 percent. This is the standard measure of response, namely the number of completed replies divided by the number of eligible reporting units in the sample. In view of the broad scope and volume of the information sought, the 1986 survey compares favorably with the prior National Center for Health Statistics (NCHS) mortality followback surveys, which produced response rates ranging from 91 to 93 percent.

Younger decedents and black decedents, two population groups oversampled in the 1986 survey, yielded lower response rates than other groups of decedents surveyed. The weighted completion rate, which is an estimate of the result if all deaths in the United States had been surveyed without oversampling, was 88.5 percent.

Another useful measure of survey response, designed to reveal the level of cooperation from the population surveyed, merits examination. This measure deletes from the denominator those cases in which no informant was reached and therefore no reply could be expected. In the mail phase of the survey, no response was possible for 58 decedents for the following reasons:

- *No informant could be identified*—50 cases
- *It was learned that the informant was deceased, and no new informant could be identified*—8 cases

Thus, with 16,598 questionnaires completed, out of potential replies from 18,675 informants reached, a completion rate of 88.9 percent is observed.

Age of decedent

The percent of completion of the questionnaires increased directly as the age of the decedent increased. The response rate for decedents 85 years of age and over was 92.4 percent, compared with a rate of 85.1 percent for those 25–44 years of age. For each age group in between, the response was better as the age increased (table 2).

Sex of decedent

The response rate for female decedents was higher than that for males, with a completion level of 89.7 percent and 87.7 percent, respectively. Refusals were higher

for male decedents, 8.1 percent, compared with 6.7 percent for females (table 2).

Race of decedent

The highest response rate among the racial groups was found in the American Indian, Aleut, and Eskimo population, with 90.7 percent completing the questionnaires. Black decedents were reported on at a rate of 88.7 percent and white decedents at 88.5 percent. The rate for other races was 87.0 percent (table 2).

Cause of death

External causes of death, including Accident, Suicide and Homicide, accounted for 11.0 percent of the sample studied. Informants for these decedents responded substantively for 83.8 percent of these inquiries, a lower rate than the 89.2 percent response for natural causes of death, and lower than for any other major cause (table 3). Refusals for external causes were 9.3 percent, compared with 7.1 percent for natural causes. Two characteristics of the external causes of death may account for the lower response rate. These causes include Suicides and Homicides, and relatives may have been reluctant to discuss the death. Furthermore, deaths from external causes are usually sudden, unexpected, and early in life—characteristics that may have increased family reluctance to respond to an inquiry about the death.

When the response rates for 11 major natural causes of death are examined, the rates vary within a generally narrow range. Of the 11 causes, only 3 fall more than 2 percentage points above or below the survey average of 88.6 percent response.

Geographic area

The most significant variation in response by State occurred for Pennsylvania, where personal visits were restricted to informants who provided written consent for such a visit. (See discussion under "Survey procedures.") Pennsylvania is a populous State, with 5.9 percent of all deaths in the United States in 1986. Completed responses for decedents who were residents of Pennsylvania were returned for only 55.3 percent of the Pennsylvania sample, compared with 88.6 percent for the total survey. The refusal rate for Pennsylvania was 33.4 percent, compared with a rate of 7.5 percent for the total survey.

If the deaths in Pennsylvania had been excluded because of the restricted survey procedure, the response rate for the general survey would be 90.5 percent.

Because of the low Pennsylvania response, the completion rate for the Northeast region was 77.5 percent. The rate for the other three regions of the country were 90.3, 91.3, and 92.6 percent.

Response by veteran status

The death certificate reported that the decedent was a veteran of the United States Armed Forces for 16.8 percent

of the decedents in the survey sample. Nonveteran status was reported on 57.8 percent of the certificates. The veteran status was unspecified on 25.5 percent of the certificates. The response rate for veterans was 88.4 percent, essentially the same as for nonveterans (88.9 percent).

Response by marital status

Married decedents constituted 47.2 percent of the sample; substantive responses were received for 88.8 percent of them (table 4). Widowed decedents represented 29.0 percent of the sample and had a response rate of 90.8 percent. Never-married status was reported for 12.8 percent of the decedents; completed questionnaires were received for 85.1 percent of these decedents. Divorced persons composed 10.2 percent of the survey sample, and had a response rate of 87.4 percent. The marital status was unspecified in 0.6 percent of the death certificates; responses were received for 64.5 percent of these decedents.

Response by relationship of informant to decedent

The relationship specified was that of the informant to the decedent; for example, "son or daughter" means that the informant was the son or daughter of the decedent. Two sources of the relationship of the informant to the decedent were examined: the relationship reported on the death certificate and that reported on the questionnaire. The outstanding feature of the death certificate relationship was the large number of unspecified relationships, 35.1 percent (table 5). A spouse was reported as the informant on the greatest number of death certificates, 37.6 percent of the sample records. The informant was the parent of the decedent on 7.5 percent of the certificates, the son or daughter on 10.8 percent, a sibling on 3.8 percent, another relative on 2.8 percent, and a nonrelative on 2.4 percent.

The only means of examining the response rates by relationship of the informant to the decedent is to use the death certificate report of that relationship as the denominator. This measure has limitations because the relationship as reported by the informant on the questionnaire may differ from the death certificate record. However, using this measure yields response rates of 88.5 percent for records mailed to a spouse, 86.6 percent for a parent, 90.6 percent for a son or daughter, 88.1 percent for a sibling, 93.3 percent for other relatives, 86.8 percent for nonrelatives, and 88.4 percent for unspecified relationship (table 4).

Results of a comparison of the relationship of the informant to the decedent, as recorded on the death certificate, with the relationship as reported by the informant on the questionnaire are shown in table 5. Differences in the two sources do not necessarily mean that there are true discrepancies, since the person completing the questionnaire may be a different person from the one

addressed in the initial mailing or an informant identified by the funeral director or hospital after the survey began. The following differences were observed:

- For a spouse, 37.6 percent on the death certificate and 35.3 percent on the questionnaire
- For sons or daughters, 10.8 percent on the certificate and 27.4 percent on the questionnaire
- For parents, 7.5 percent on the death certificates and 9.5 percent on the questionnaire
- For siblings, 3.8 percent on the certificates and 9.8 percent on the questionnaire
- For other relatives, 2.8 percent on the death certificate and 11.3 percent on the questionnaire
- For nonrelatives, 2.4 percent on the certificate and 4.5 percent on the questionnaire
- For the unspecified category, 35.1 percent on the certificate and 0.8 percent on the questionnaire. This means that an informant was identified later, usually by contacting the funeral director or hospital.

The 245 interviews completed by a staff person in a nursing home could have no such entry on the death certificate.

Response by autopsy status

The performance of an autopsy was reported on 18.1 percent of the death certificates in the sample, with 70.7 percent stating that no autopsy was performed and 11.2 percent with unspecified status. The response rate for decedents on whom an autopsy was performed was 84.6 percent, compared with 89.4 percent when no autopsy was recorded. Those with unspecified status had a response rate of 90.0 percent.

Autopsies are generally performed by medical examiners in cases of external causes of death, and, as noted above, these deaths showed a lower response rate.

Response by survey method

Of the 16,598 completed records in the survey, 9,458 (57.0 percent) were returned by mail. Telephone interviews yielded 30.2 percent of all completed responses, and personal interviews accounted for 12.4 percent of the completions. The method of completion of the questionnaire was not ascertainable for 74 decedents.

Authorization statements from informants

Of the 16,598 completed questionnaires, an Authorization to Obtain Information from Medical Records was signed by informants or approved by proxy respondents on 14,152 records (85.3 percent).

Response from facilities

A total of 17,668 Facility Abstract Record (FAR) forms was prepared for mailing. Information to enter on these forms was obtained from three sources: the

informant questionnaire, the death certificate, and another facility used by the decedent in the last year of life. Of these forms, 1,238 were not mailed for administrative reasons, largely because Pennsylvania prohibited mailings to facilities in that State when no authorization was received from the informant. Thus, 16,430 FAR's were mailed in an attempt to secure facility data.

In four cases, no adequate address for the informant could be found when the initial mailing was returned by the post office. Eliminating these 4 cases leaves 16,426 FAR's for which a reply could be expected.

Through clerical error, the Census Bureau, which conducted the data gathering, failed to record on the control form a final response status for 2,272 cases. A record was made that no response was received for 1,048 FAR's. Thus the control record shows that a response was received for 13,106 FAR's. Given the unknown response status for 2,272 records and assuming the worst case—that none of these replied—the response rate would be 79.8 percent.

Of the 13,106 FAR's replies received, the Census Bureau reported that 11,814 respondent facilities sent completed forms; 1,290 responded that there was no record of the decedent in that facility; and 2 sent unacceptable facsimile records.

The edited public-use data tape contains 30,165 episodes of care for the survey decedents. As seen in table Q, among the decedents with at least 1 FAR, 8,437 decedents (68.7 percent) had one completed FAR on the tape, 3,066 (25.0 percent) had 2; and 772 (6.3 percent) had 3 or more.

Table R shows that, among those decedents with at least 1 completed FAR, 5,046 (41.1 percent) had 1 episode of facility care in the last year of life; 2,779 (22.6 percent) had 2; 1,790 (14.6 percent) had 3; 1,080 (8.8 percent) had 4; 730 (5.9 percent) had 5; and 850 (6.9 percent) had 6 or more.

The public-use data tape also includes information on the length of stay, the diagnoses, and the procedures used.

Because the public-use data tape does not have weights to adjust for nonresponse from facilities, caution must be exercised in analyzing and interpreting these data.

A summary of the significant findings of the 1986 National Mortality Followback Survey (NMFS) was published by NCHS as *Vital and Health Statistics*, Series 20, Number 19 (28).

Table Q. Number and percent distribution of decedents with Facility Abstract Record by number of facilities used in last year of life: National Mortality Followback Survey, 1986

	Number of facilities used	Number of decedents	Percent distribution of decedents
Total		12,275	100.0
1		8,437	68.7
2		3,066	25.0
3		659	5.4
4		90	0.7
5		20	0.2
6		3	0.0

Table R. Number and percent distribution of decedents with Facility Abstract Record by number of episodes of care in last year of life: National Mortality Followback Survey, 1986

<i>Number of episodes</i>	<i>Number of decedents</i>	<i>Percent distribution of decedents</i>
Total	12,275	100.0
1	5,046	41.1
2	2,779	22.6
3	1,790	14.6
4	1,080	8.8
5	730	5.9
6	360	2.9
7	237	1.9
8	109	0.9
9	61	0.5
10	32	0.3
11	15	0.1
12	13	0.1
13	7	0.1
14	7	0.1
15	3	0.0
16	2	0.0
17	2	0.0
18	—	—
19	—	—
20	2	0.0

NOTE: Percents may not add to totals due to rounding.

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Table 1. Number and percent distribution of informant responses by response status: National Mortality Followback Survey, 1986

<i>Response status¹</i>	<i>Number</i>	<i>Percent distribution</i>
All responses	18,733	100.0
Completed responses	16,598	88.6
Complete	15,539	82.9
Fail-edit (mail)	747	4.0
Partially completed (field)	312	1.7
Refused	1,400	7.5
Cannot contact—beyond 50 miles	59	0.3
Cannot contact—other reason	258	1.4
Cannot locate (field)	301	1.6
Other noninterview	67	0.4
No informant (mail)	50	0.3

¹For the definitions of these terms, see "Response characteristics."

NOTE: Percents may not add to totals due to rounding.

Table 2. Number and percent distribution of informant responses by response status, according to sex, race, and age of decedent: National Mortality Followback Survey, 1986

<i>Sex, race, and age of decedent</i>	<i>Response status</i>									
	<i>Total</i>	<i>Completed</i>	<i>Refused</i>	<i>No response</i>	<i>No informant</i>	<i>Total</i>	<i>Completed</i>	<i>Refused</i>	<i>No response</i>	<i>No informant</i>
	<i>Number</i>					<i>Percent distribution</i>				
Both sexes										
All races, 25 years and over	18,733	16,598	1,400	685	50	100.0	88.6	7.5	3.7	0.3
25–44 years	4,299	3,658	366	253	22	100.0	85.1	8.5	5.9	0.5
45–64 years	4,280	3,753	325	194	8	100.0	87.7	7.6	4.5	0.2
65–74 years	3,496	3,104	276	105	11	100.0	88.8	7.9	3.0	0.3
75–84 years	3,895	3,530	285	76	4	100.0	90.6	7.3	2.0	0.1
85 years and over	2,763	2,553	148	57	5	100.0	92.4	5.4	2.1	0.2
White, 25 years and over	13,303	11,771	1,102	397	33	100.0	88.5	8.3	3.0	0.2
25–44 years	3,189	2,708	293	172	16	100.0	84.9	9.2	5.4	0.5
45–64 years	2,803	2,461	241	96	5	100.0	87.8	8.6	3.4	0.2
65–74 years	2,363	2,093	207	57	6	100.0	88.6	8.8	2.4	0.3
75–84 years	2,818	2,546	233	36	3	100.0	90.3	8.3	1.3	0.1
85 years and over	2,130	1,963	128	36	3	100.0	92.2	6.0	1.7	0.1
Black, 25 years and over	4,759	4,223	273	250	13	100.0	88.7	5.7	5.3	0.3
25–44 years	943	804	66	68	5	100.0	85.3	7.0	7.2	0.5
45–64 years	1,292	1,128	76	86	2	100.0	87.3	5.9	6.7	0.2
65–74 years	1,031	918	65	44	4	100.0	89.0	6.3	4.3	0.4
75–84 years	946	866	47	33	—	100.0	91.5	5.0	3.5	—
85 years and over	547	507	19	19	2	100.0	92.7	3.5	3.5	0.4
American Indian, 25 years and over	540	490	18	29	3	100.0	90.7	3.3	5.4	0.6
25–44 years	118	104	4	9	1	100.0	88.1	3.4	7.6	0.8
45–64 years	157	140	6	11	—	100.0	89.2	3.8	7.0	—
65–74 years	85	78	3	3	1	100.0	91.8	3.5	3.5	1.2
75–84 years	112	102	4	5	1	100.0	91.1	3.6	4.5	0.9
85 years and over	68	66	1	1	—	100.0	97.1	1.5	1.5	—
Other races, 25 years and over	131	114	7	9	1	100.0	87.0	5.3	6.9	0.8
25–44 years	49	42	3	4	—	100.0	85.7	6.1	8.2	—
45–64 years	28	24	2	1	1	100.0	85.7	7.1	3.6	3.6
65–74 years	17	15	1	1	—	100.0	88.2	5.9	5.9	—
75–84 years	19	16	1	2	—	100.0	84.2	5.3	10.5	—
85 years and over	18	17	—	1	—	100.0	94.4	—	5.6	—

Table 2. Number and percent distribution of informant responses by response status, according to sex, race, and age of decedent: National Mortality Followback Survey, 1986—Con.

Sex, race, and age of decedent	Response status									
	Total	Completed	Refused	No response	No informant	Total	Completed	Refused	No response	No informant
	Number					Percent distribution				
Male										
All races, 25 years and over	10,238	8,978	831	390	39	100.0	87.7	8.1	3.8	0.4
25-44 years	3,033	2,565	266	183	19	100.0	84.6	8.8	6.0	0.6
45-64 years	2,393	2,099	201	85	8	100.0	87.7	8.4	3.6	0.3
65-74 years	1,961	1,731	156	65	9	100.0	88.3	8.0	3.3	0.5
75-84 years	1,901	1,713	147	40	1	100.0	90.1	7.7	2.1	0.1
85 years and over	950	870	61	17	2	100.0	91.6	6.4	1.8	0.2
White, 25 years and over	7,339	6,412	673	229	25	100.0	87.4	9.2	3.1	0.3
25-44 years	2,286	1,932	216	124	14	100.0	84.5	9.4	5.4	0.6
45-64 years	1,570	1,374	150	41	5	100.0	87.5	9.6	2.6	0.3
65-74 years	1,369	1,200	130	34	5	100.0	87.7	9.5	2.5	0.4
75-84 years	1,390	1,243	126	21	—	100.0	89.4	9.1	1.5	—
85 years and over	724	663	51	9	1	100.0	91.6	7.0	1.2	0.1
Black, 25 years and over	2,533	2,236	143	143	11	100.0	88.3	5.6	5.6	0.4
25-44 years	633	530	47	51	5	100.0	83.7	7.4	8.1	0.8
45-64 years	718	630	46	40	2	100.0	87.7	6.4	5.6	0.3
65-74 years	538	482	23	30	3	100.0	89.6	4.3	5.6	0.6
75-84 years	454	420	18	16	—	100.0	92.5	4.0	3.5	—
85 years and over	190	174	9	6	1	100.0	91.6	4.7	3.2	0.5
American Indian, 25 years and over	289	261	11	15	2	100.0	90.3	3.8	5.2	0.7
25-44 years	81	74	1	6	—	100.0	91.4	1.2	7.4	—
45-64 years	93	84	5	4	—	100.0	90.3	5.4	4.3	—
65-74 years	44	40	2	1	1	100.0	90.9	4.5	2.3	2.3
75-84 years	46	40	2	3	1	100.0	87.0	4.3	6.5	2.2
85 years and over	25	23	1	1	—	100.0	92.0	4.0	4.0	—
Other races, 25 years and over	77	69	4	3	1	100.0	89.6	5.2	3.9	1.3
25-44 years	33	29	2	2	—	100.0	87.9	6.1	6.1	—
45-64 years	12	11	—	—	1	100.0	91.7	—	—	8.3
65-74 years	10	9	1	—	—	100.0	90.0	10.0	—	—
75-84 years	11	10	1	—	—	100.0	90.9	9.1	—	—
85 years and over	11	10	—	1	—	100.0	90.9	—	9.1	—
Female										
All races, 25 years and over	8,495	7,620	569	295	11	100.0	89.7	6.7	3.5	0.1
25-44 years	1,266	1,093	100	70	3	100.0	86.3	7.9	5.5	0.2
45-64 years	1,887	1,654	124	109	—	100.0	87.7	6.6	5.8	—
65-74 years	1,535	1,373	120	40	2	100.0	89.4	7.8	2.6	0.1
75-84 years	1,994	1,817	138	36	3	100.0	91.1	6.9	1.8	0.2
85 years and over	1,813	1,683	87	40	3	100.0	92.8	4.8	2.2	0.2
White, 25 years and over	5,964	5,359	429	168	8	100.0	89.9	7.2	2.8	0.1
25-44 years	903	776	77	48	2	100.0	85.9	8.5	5.3	0.2
45-64 years	1,233	1,087	91	55	—	100.0	88.2	7.4	4.5	—
65-74 years	994	893	77	23	1	100.0	89.8	7.7	2.3	0.1
75-84 years	1,428	1,303	107	15	3	100.0	91.2	7.5	1.1	0.2
85 years and over	1,406	1,300	77	27	2	100.0	92.5	5.5	1.9	0.1
Black, 25 years and over	2,226	1,987	130	107	2	100.0	89.3	5.8	4.8	0.1
25-44 years	310	274	19	17	—	100.0	88.4	6.1	5.5	—
45-64 years	574	498	30	46	—	100.0	86.8	5.2	8.0	—
65-74 years	493	436	42	14	1	100.0	88.4	8.5	2.8	0.2
75-84 years	492	446	29	17	—	100.0	90.7	5.9	3.5	—
85 years and over	357	333	10	13	1	100.0	93.3	2.8	3.6	0.3
American Indian, 25 years and over	251	229	7	14	1	100.0	91.2	2.8	5.6	0.4
25-44 years	37	30	3	3	1	100.0	81.1	8.1	8.1	2.7
45-64 years	64	56	1	7	—	100.0	87.5	1.6	10.9	—
65-74 years	41	38	1	2	—	100.0	92.7	2.4	4.9	—
75-84 years	66	62	2	2	—	100.0	93.9	3.0	3.0	—
85 years and over	43	43	—	—	—	100.0	100.0	—	—	—
Other races, 25 years and over	54	45	3	6	—	100.0	83.3	5.6	11.1	—
25-44 years	16	13	1	2	—	100.0	81.3	6.3	12.5	—
45-64 years	16	13	2	1	—	100.0	81.3	12.5	6.3	—
65-74 years	7	6	—	1	—	100.0	85.7	—	14.3	—
75-84 years	8	6	—	2	—	100.0	75.0	—	25.0	—
85 years and over	7	7	—	—	—	100.0	100.0	—	—	—

NOTE: These data are unweighted. Percents may not add to totals due to rounding.

Table 3. Number and percent distribution of informant responses by response status, according to cause of death of the decedent: National Mortality Followback Survey, 1986

Cause of death and ICD-9 code	Response status									
	Total	Completed	Refused	No response	No informant	Total	Completed	Refused	No response	No informant
	Number					Percent distribution				
All causes ¹	18,707	16,577	1,376	685	49	100.0	88.6	7.5	3.7	0.3
Infectious and parasitic diseases001-139	323	278	29	15	1	100.0	86.1	9.0	4.6	0.3
Malignant neoplasms140-208	4,000	3,562	304	130	4	100.0	89.1	7.6	3.3	0.1
Diabetes mellitus250	351	311	26	14	-	100.0	88.6	7.4	4.0	-
Major cardiovascular diseases ²390-448	8,164	7,343	548	255	18	100.0	89.9	6.7	3.1	0.2
Diseases of heart ²390-398,402,404-429	6,680	5,987	465	211	17	100.0	89.6	7.0	3.2	0.3
Ischemic heart disease410-414	4,729	4,249	336	134	10	100.0	89.9	7.1	2.8	0.2
Cerebrovascular diseases430-438	1,122	1,018	67	37	-	100.0	90.7	6.0	3.3	-
Pneumonia and influenza480-487	519	468	36	10	5	100.0	90.2	6.9	1.9	1.0
Chronic obstructive pulmonary diseases and allied conditions490-496	788	709	57	20	2	100.0	90.0	7.2	2.5	0.3
Chronic liver disease and cirrhosis571	300	253	27	16	4	100.0	84.3	9.0	5.3	1.3
Nephritis, nephrotic syndrome, and nephrosis580-589	185	161	19	5	-	100.0	87.0	10.3	2.7	-
External causes of injury and poisoning ²E800-E999	2,056	1,723	191	132	10	100.0	83.8	9.3	6.4	0.5
Accidents and adverse effectsE800-E949	1,143	982	96	60	5	100.0	85.9	8.4	5.3	0.4
SuicideE950-E959	485	401	54	29	1	100.0	82.7	11.1	6.0	0.2
Homicide and legal interventionE960-E978	383	308	33	39	3	100.0	80.4	8.6	10.2	0.8
All other causes	2,428	2,139	183	99	7	100.0	88.1	7.5	4.1	0.3

¹The informant questionnaire and the death certificate could not be matched for 26 records. The total sample included 18,733 records.

²Includes figures for subcategories not shown separately.

NOTES: These data are unweighted. Percents may not add to totals due to rounding.

Table 4. Number and percent distribution of informant responses by response status, according to decedent's marital status and relationship of informant to decedent: National Mortality Followback Survey, 1986

Decedent's marital status and relationship of informant to decedent	Response status									
	Total	Completed	Refused	No response	No informant	Total	Completed	Refused	No response	No informant
	Number					Percent distribution				
Marital status of decedent										
All decedents	18,733	16,598	1,400	685	50	100.0	88.6	7.5	3.7	0.3
Married	8,851	7,862	706	278	5	100.0	88.8	8.0	3.1	0.1
Widowed	5,424	4,923	324	173	4	100.0	90.8	6.0	3.2	0.1
Divorced	1,916	1,674	138	97	7	100.0	87.4	7.2	5.1	0.4
Never married	2,406	2,047	215	128	16	100.0	85.1	8.9	5.3	0.7
Not stated	110	71	13	9	17	100.0	64.6	11.8	8.2	15.5
Record not matched	26	21	4	-	1	100.0	80.8	15.4	-	3.8
Relationship of informant to decedent										
Informant was decedent's--										
Husband or wife	7,040	6,228	596	214	2	100.0	88.5	8.5	3.0	0.0
Father or mother	1,411	1,222	124	64	1	100.0	86.6	8.8	4.5	0.1
Son or daughter	2,018	1,828	112	78	-	100.0	90.6	5.6	3.9	-
Brother or sister	713	628	51	34	-	100.0	88.1	7.2	4.8	-
Other relative	523	488	19	16	-	100.0	93.3	3.6	3.1	-
Nonrelative	455	395	30	25	5	100.0	86.8	6.6	5.5	1.1
Not stated	6,573	5,809	468	254	42	100.0	88.4	7.1	3.9	0.6

NOTES: These data are unweighted. Percents may not add to totals due to rounding.

Table 5. Number and percent distribution of informants as reported on the death certificate and on the informant questionnaire, by relationship of the informant to decedent: National Mortality Followback Survey, 1986

<i>Relationship of informant to decedent</i>	<i>Death certificate</i>		<i>Informant questionnaire</i>	
	Number	Percent distribution	Number	Percent distribution
Total	18,733	100.0	16,598	100.0
Informant was decedent's—				
Husband or wife	7,040	37.6	5,853	35.3
Son or daughter	2,018	10.8	4,548	27.4
Father or mother	1,411	7.5	1,577	9.5
Brother or sister	713	3.8	1,623	9.8
Other relative	523	2.8	1,872	11.3
Nonrelative	455	2.4	747	4.5
Staff person in a nursing home	—	—	245	1.5
Not specified	6,573	35.1	133	0.8

NOTE: Percents may not add to totals due to rounding.

Appendixes

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Appendix I

Definitions of certain terms used in the survey

Age—The age of the decedent at the time of death as recorded on the death certificate or as reported by the informant on the questionnaire.

Current Mortality Sample—A systematic 10-percent sample of death certificates filed with the State vital statistics registrars and forwarded to the National Center for Health Statistics each month. This file is the universe from which the survey sample was drawn.

Decedent—An individual for whom a death certificate was filed in the office of the vital statistics registrar of the State in which the death occurred.

Don't know—This classification indicates that the informant failed to provide a usable response to an item. The instructions to the informants asked them to put a question mark or write "Don't know" if they did not have the information on a question. Such responses were coded into three categories: "Multiple answers," "Refused," and "Don't know."

Facility Abstract Record (FAR)—The questionnaire form mailed to hospitals, nursing homes, and other health care facilities used by the decedent in the last year of life.

Health care facility—Acute care and chronic disease hospitals, mental hospitals, drug and alcohol treatment centers, nursing homes, hospices, and other health service institutions providing overnight care. Excluded are personal care homes, homes for the aged, board and care homes, and other facilities not providing nursing care or other health services.

Hispanic—This is not a racial classification, but a category of origin or descent. The questionnaire included this question about the decedent: "Was of Spanish or Hispanic origin or descent?"

Hospice—This term applies to both at-home and institutional care. It represents health and personal care services provided to dying persons.

Informant or respondent—In this report, this is the individual who responded to the survey questionnaire. This individual may or may not have been the informant listed on the death certificate who provided the personal information about the decedent to the funeral director who filed the death certificate. The questionnaires were

mailed to the informants listed on the death certificates, but sometimes another person completed the questionnaire.

Interview—The completion of a questionnaire by a representative of the U.S. Bureau of the Census, either by telephone or by in-person contact with the informant.

Last year of life—The full calendar year prior to the date on which the death occurred.

Living will—A document executed by an individual to express his or her preferences with regard to care and treatment, such as life-sustaining equipment or procedures, to be provided or to be withheld or withdrawn in the event that the individual has a terminal illness or other condition from which recovery is not expected.

Medicare—The medical assistance provided in Title XVIII of the Social Security Act. Medicare is a health insurance program administered by the Health Care Financing Administration for persons 65 years old and over and for disabled persons who are eligible for benefits.

Multiple Cause-of-Death File—The final file of death certificates compiled by NCHS after the close of the year, including records on which additional information or corrections have been entered after the Current Mortality Sample (CMS) certificate was filed.

Out-of-universe—This code was entered when the item did not apply to the decedent. It reflects primarily skip patterns. This code would be entered, for example, in the item on duration of angina if the informant responded that the decedent did not have angina, and it would apply to males in a female-specific question such as use of birth control pills.

Race—The race of the decedent as recorded on the death certificate or as reported by the informant on the questionnaire. The classifications used are the four race classifications defined by the U.S. Office of Management and Budget. These are: white; black; American Indian, Aleut, and Eskimo; and other races.

Refusal—If a spouse or other person residing at the decedent's address refused, no further effort was made. If another informant refused, some other family member was sought.

Appendix II

U.S. Standard Certificate of Death

(PHYSICIAN, MEDICAL EXAMINER OR CORONER)
U.S. STANDARD
CERTIFICATE OF DEATH

Form Approved
OMB No. 68R 1901

LOCAL FILE NUMBER		STATE FILE NUMBER	
DECEDENT—NAME FIRST MIDDLE LAST		SEX	DATE OF DEATH (Mo., Day, Yr.)
1. RACE—(e.g., White, Black, American Indian, etc.) (Specify)		2. COUNTY OF DEATH	
4. AGE—Last Birthday (Yrs.)		6. DATE OF BIRTH (Mo., Day, Yr.)	
5a. UNDER 1 YEAR		5c. UNDER 1 DAY	
5b. MOS. DAYS		5d. HOURS MINS.	
7b. CITY, TOWN OR LOCATION OF DEATH		7c. HOSPITAL OR OTHER INSTITUTION—Name (If not in either, give street and number)	
7d. STATE OF BIRTH (If not in U.S.A., name country)		7e. CITIZEN OF WHAT COUNTRY	
8. SOCIAL SECURITY NUMBER		10. MARRIED, NEVER MARRIED, WIDOWED, DIVORCED (Specify)	
13. RESIDENCE—STATE		14a. USUAL OCCUPATION (Give kind of work done during most of working life, even if retired)	
15a. COUNTY		14b. KIND OF BUSINESS OR INDUSTRY	
15b. CITY, TOWN OR LOCATION		15d. STREET AND NUMBER	
15c. INSIDE CITY LIMITS (Specify Yes or No)		15e.	
FATHER—NAME FIRST MIDDLE LAST		MOTHER—MAIDEN NAME FIRST MIDDLE LAST	
16. INFORMANT—NAME (Type or Print)		17. MAILING ADDRESS	
18a. BURIAL, CREMATION, REMOVAL, OTHER (Specify)		18b. CEMETERY OR CREMATORY—NAME	
19a. FUNERAL SERVICE LICENSEE Or Person Acting As Such (Signature)		19b. NAME OF FACILITY	
20a.		20c. ADDRESS OF FACILITY	
20b.		20d.	
21a. To the best of my knowledge, death occurred at the time, date and place and due to the cause(s) stated.		22a. On the basis of examination and/or investigation, in my opinion death occurred at the time, date and place and due to the cause(s) stated.	
(Signature and Title)		(Signature and Title)	
DATE SIGNED (Mo., Day, Yr.)		DATE SIGNED (Mo., Day, Yr.)	
21b. NAME OF ATTENDING PHYSICIAN IF OTHER THAN CERTIFIER (Type or Print)		22b. PRONOUNCED DEAD (Mo., Day, Yr.)	
21c. HOUR OF DEATH		22c. PRONOUNCED DEAD (Hour)	
21d. NAME AND ADDRESS OF CERTIFIER (PHYSICIAN, MEDICAL EXAMINER OR CORONER) (Type or Print)		22d. ON	
21e. M		22e. AT	
21f. M		22f. AT	
21g. M		22g. AT	
21h. M		22h. AT	
21i. M		22i. AT	
21j. M		22j. AT	
21k. M		22k. AT	
21l. M		22l. AT	
21m. M		22m. AT	
21n. M		22n. AT	
21o. M		22o. AT	
21p. M		22p. AT	
21q. M		22q. AT	
21r. M		22r. AT	
21s. M		22s. AT	
21t. M		22t. AT	
21u. M		22u. AT	
21v. M		22v. AT	
21w. M		22w. AT	
21x. M		22x. AT	
21y. M		22y. AT	
21z. M		22z. AT	
23. REGISTRAR		DATE RECEIVED BY REGISTRAR (Mo., Day, Yr.)	
24a. (Signature)		24b.	
25. IMMEDIATE CAUSE [ENTER ONLY ONE CAUSE PER LINE FOR (a), (b), AND (c).]		Interval between onset and death	
(a) DUE TO, OR AS A CONSEQUENCE OF:		Interval between onset and death	
(b) DUE TO, OR AS A CONSEQUENCE OF:		Interval between onset and death	
(c) DUE TO, OR AS A CONSEQUENCE OF:		Interval between onset and death	
PART II OTHER SIGNIFICANT CONDITIONS—Conditions contributing to death but not related to cause given in PART I (a)		AUTOPSY (Specify Yes or No)	
26a. ACC., SUICIDE, HOM., UNDET., OR PENDING INVEST. (Specify)		26. WAS CASE REFERRED TO MEDICAL EXAMINER OR CORONER (Specify Yes or No)	
28a. DATE OF INJURY (Mo., Day, Yr.)		27.	
28b. HOUR OF INJURY		27.	
28c. DESCRIBE HOW INJURY OCCURRED		27.	
28d. INJURY AT WORK (Specify Yes or No)		27.	
28e. PLACE OF INJURY—At home, farm, street, factory, office building, etc. (Specify)		27.	
28f. LOCATION		27.	
28g. STREET OR R.F.D. No.		27.	
28h. CITY OR TOWN		27.	
28i. STATE		27.	

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE—PUBLIC HEALTH SERVICE—NATIONAL CENTER FOR HEALTH STATISTICS
1978 REVISION

TYPE OR PRINT IN PERMANENT INK FOR INSTRUCTIONS SEE HANDBOOK

DECEDENT
IF DEATH OCCURRED IN INSTITUTION, SEE HANDBOOK REGARDING COMPLETION OF RESIDENCE ITEMS.

PARENTS

DISPOSITION

CERTIFIER

CAUSE OF DEATH
CONDITIONS IF ANY WHICH GAVE RISE TO IMMEDIATE CAUSE STATING THE UNDERLYING CAUSE LAST

HRA-162-1
Rev. 1/78

Appendix III

Inventory of National Mortality Followback Survey forms

NMF-1	First mailout, self-response informant questionnaire	NMF-6A	Decedent Control Form used by Census Bureau in the facility phase to list facilities used by a sample decedent
NMF-10(L) ID	State of Idaho endorsement letter for all Idaho deaths	NMF-6B	Facility Control Form used by Census Bureau staff in the facility phase to list the decedents who stayed in a particular facility
NMF-11 (PA)	Pennsylvania consent forms	NMF-60(L)	Letter sent to Medical Records Administrator to request participation in the facility phase
NMF-2	Second mailout, self-response informant questionnaire for nonrespondents to NMF-1 mailout	NMF-61(L)	Letter sent to administrators to request participation in the facility phase
NMF-30(L)	Reminder/Thank you letter sent to all informants 10 days after NMF-1 mailout	NMF-60(L) ID	Medical Record Letter and Administrator
NMF-4	Field followup questionnaire for nonrespondents to the NMF-1 and NMF-2 mailouts	NMF-61(L) ID	Endorsement letter from State of Idaho for Idaho deaths
NMF-4A	Proxy Consent Statement for fail-edit followup with informants who failed to sign the original statement	NMF-62(L)	American Medical Records Association Endorsement Letter for the facility phase
NMF-40(L)	Introductory letter used in field followup with informants who did not receive the NMF-1 or NMF-2 questionnaires	NMF-63(L)	American Hospital Association Endorsement Letter for facility phase
NMF-41	Flashcard Booklet used in personal visit interviews	NMF-7	Address Request Form for use when informants' names and addresses could not be obtained by telephone
NMF-5	Staff questionnaire used in field followup for informants who were staff members of facilities	NMF-70(L)	Cover Letter for the NMF-7 requests to funeral directors
NMF-50(L)	Administrator Letter sent to administrators who requested information about the survey during an NMF-5 interview	NMF-71(L)	Cover Letter for the NMF-7 to sources other than funeral directors
NMF-6	Facility Abstract Record completed by facilities	NMF-8	Reinterview questionnaire

PGM 2

1

OMB No. 0937-0144: Approval Expires December 31, 1987


DEPARTMENT OF HEALTH & HUMAN SERVICES

 Public Health Service
 National Center for Health Statistics

 FORM **NMF-1**
 (5-2-86)

 U.S. DEPARTMENT OF COMMERCE
 BUREAU OF THE CENSUS
 ACTING AS COLLECTING AGENT FOR THE
 U.S. PUBLIC HEALTH SERVICE

1986 NATIONAL MORTALITY FOLLOWBACK SURVEY
**Appendix IV
 National Mortality
 Followback Survey
 Informant Questionnaire
 (NMF-1)**
FROM THE DIRECTOR

You can help the U.S. Public Health Service to learn more about ways to prevent illness and to improve care for sick and dying persons. You or a relative provided some of the information that was included on the death certificate for the person named above. This information is helpful in understanding about deaths from various causes. Still, we need to learn more so that we can assure the best health care for ill persons and prevent early death when possible. We are therefore having the Bureau of the Census conduct a survey for us, and have randomly selected a sample of deaths in the United States in 1985 and 1986. We ask you to complete this questionnaire about the life and death of the person named above, even if the person died from old age or an accident.

We know that this reminder of the person who died recently may be painful, but we believe that you will want to help others, and your answers will do that. Some of the questions may be difficult to answer, and you may not know the answers to all of them. Many questions may not apply to the person because we are using the same form for all persons in the study. We ask you to recall, to the best of your ability, and answer all that you can. A few general instructions appear on page 2.

All of your answers are strictly confidential. The identity of individuals will not be disclosed by either the Bureau of the Census or the Public Health Service without your written approval. We will not include any information that could identify an individual in the statistics we release. This survey is voluntary and is authorized by the Public Health Service Act (Title 42, United States Code, Section 242k). To add to our knowledge, we are requesting your authorization to secure medical information from hospitals or other health care facilities used by the person in the last year of life.

Although there are no penalties for failing to reply, each unanswered question substantially lessens the accuracy of the final data. The success of this study depends on receiving information on every questionnaire we send out. Your reply is extremely important. Please mail the completed form to the Bureau of the Census within 5 DAYS in the enclosed envelope which requires no postage. Your prompt attention to this request is appreciated.

Sincerely yours,

Manning Feinleib, M.D., Dr. P.H.

(Please correct any error in name and address including ZIP Code.)

NOTICE — Information contained on this form which would permit identification of any individual or establishment has been collected with a guarantee that it will be held in strict confidence, will be used only for purposes stated for this study, and will not be disclosed or released to others without the consent of the individual or the establishment in accordance with Section 308(d) of the Public Health Service Act (42 USC 242m).

**PLEASE RETURN
 WITHIN 5 DAYS
 TO —**
**Bureau of the Census
 1201 East Tenth Street
 Jeffersonville, Indiana 47132**

INSTRUCTIONS

1. Several items on this form refer to the person's last year of life. This means the time starting one year before the date of death and ending on the day of death. **Example:** If the date of death was January 5, 1986, the period referred to as the "last year of life" is January 5, 1985, to January 5, 1986.
2. Please answer each question to the best of your ability. In some cases you may wish to refer to records or ask other persons. Some questions ask for the amount of time before death that an event occurred, for example, the amount of time before death that the person last worked. If you do not know the exact amount of time, please give your best estimate or a range. Example: 12 to 14 years; or 2 to 3 months.
3. Since some questions will not apply in all cases, instructions for which question to answer next are printed after some of the answer categories. If there is no instruction after the answer, go to the very next question.
4. If the answer does not fit one of the printed answer categories, mark the "other" box and write in the answer. If there is no "other" category, write in the answer without marking a box.
5. If you still don't know the answer to a question, put a question mark (?) or write "Don't know" in the answer space.
6. Ignore the numbers which appear in rectangles (for example 007) and any areas marked "OFFICE USE ONLY." These are for processing purposes only.
7. We welcome any additional information you wish to provide. Use the space on the last page of the questionnaire.

PLEASE BEGIN WITH PART A BELOW.

PART A — BACKGROUND INFORMATION

PGM 3

1. How old was the person at the time of death?

005

_____ Age in years

2. How was the person who died related to you?

006

Mark (X) only one box.

The person was —

- 1 My husband or wife
- 2 My father or mother
- 3 My son or daughter
- 4 My brother or sister
- 5 My neighbor or friend
- 6 Someone else — *Specify*

3. Did you ever live in the same home with the person since the person became 25 years old?

007

Do not count visits at the person's home while you had a home somewhere else.

- 1 Yes — *Go to next question*
- 2 No — *Skip to question 1 in Part B on page 3*

4. Since the person became 25 years old, how many years ALTOGETHER did you live with him or her?

008

Mark (X) only one box.

- 1 Less than one year
- 2 1 year to less than 5 years
- 3 5 years to less than 10 years
- 4 10 years to less than 20 years
- 5 20 years or more

PART B — CARE IN THE LAST YEAR OF LIFE

1. During his or her entire life, was the person ever admitted to a nursing home?

009

- 1 Yes — Go to next question
 2 No — Skip to question 3

2. What was the total amount of time the person spent in a nursing home over his or her entire lifetime?

010

Mark (X) only one box.

- 1 Less than 3 months
 2 3 months to less than 1 year
 3 1 year to less than 5 years
 4 5 years or more

3. AT ANY TIME DURING THE LAST YEAR OF LIFE, was the person an overnight patient in a hospital or a resident in a nursing home?

011

- 1 Yes — Go to next question
 2 No — Skip to question 6 on page 4

4. What were the names and addresses of all hospitals and nursing homes in which the person stayed at least one night DURING THE LAST YEAR OF LIFE? (Please give as much of the address as you can.)

012

<p>① Hospital or nursing home name _____</p> <p>Address (Number and street) _____</p> <p>City or Post Office _____</p> <p>State _____ ZIP Code _____</p>	<p>② Hospital or nursing home name _____</p> <p>Address (Number and street) _____</p> <p>City or Post Office _____</p> <p>State _____ ZIP Code _____</p>
<p>③ Hospital or nursing home name _____</p> <p>Address (Number and street) _____</p> <p>City or Post Office _____</p> <p>State _____ ZIP Code _____</p>	<p>④ Hospital or nursing home name _____</p> <p>Address (Number and street) _____</p> <p>City or Post Office _____</p> <p>State _____ ZIP Code _____</p>
<p>⑤ Hospital or nursing home name _____</p> <p>Address (Number and street) _____</p> <p>City or Post Office _____</p> <p>State _____ ZIP Code _____</p>	<p>⑥ Hospital or nursing home name _____</p> <p>Address (Number and street) _____</p> <p>City or Post Office _____</p> <p>State _____ ZIP Code _____</p>

NOTE: If more room is needed to list more hospitals or nursing homes, please continue on the last page of this questionnaire.

5. DURING THE LAST YEAR OF LIFE, how many total nights did the person spend in hospitals and nursing homes?

Number of nights during year before death

013

_____ Nights in hospital(s)

NOTE: If you are unsure, please give your best estimate.

014

_____ Nights in nursing home(s)

PART B — CARE IN THE LAST YEAR OF LIFE — Continued

6. During the last year of life, did the person stay overnight in any other type of facility providing health care?

015

- 1 Yes — Go to next question
 2 No — Skip to question 9 on page 5

Include places known as hospices, mental hospitals, drug and alcohol treatment centers, and so forth. A hospice gives care to dying persons.

7. What were the names and addresses of all these other facilities in which the person stayed during the last year of life? (Please give as much of the address as you can.)

016

<p>①</p> <p>Name of place _____</p> <p>Address (Number and street) _____</p> <p>City or Post Office _____</p> <p>State _____ ZIP Code _____</p>	<p>②</p> <p>Name of place _____</p> <p>Address (Number and street) _____</p> <p>City or Post Office _____</p> <p>State _____ ZIP Code _____</p>
<p>③</p> <p>Name of place _____</p> <p>Address (Number and street) _____</p> <p>City or Post Office _____</p> <p>State _____ ZIP Code _____</p>	<p>④</p> <p>Name of place _____</p> <p>Address (Number and street) _____</p> <p>City or Post Office _____</p> <p>State _____ ZIP Code _____</p>
<p>⑤</p> <p>Name of place _____</p> <p>Address (Number and street) _____</p> <p>City or Post Office _____</p> <p>State _____ ZIP Code _____</p>	<p>⑥</p> <p>Name of place _____</p> <p>Address (Number and street) _____</p> <p>City or Post Office _____</p> <p>State _____ ZIP Code _____</p>

NOTE: If more room is needed to list additional facilities, please continue on the last page of this questionnaire.

8. How many nights during the last year of life did the person spend in each of the places listed above?

Number of nights during year before death

NOTE: If you are unsure, please give your best estimate.

- 017 _____ Nights in first place
 018 _____ Nights in second place
 019 _____ Nights in third place
 020 _____ Nights in fourth place
 021 _____ Nights in fifth place
 022 _____ Nights in sixth place

If more than 6 places, continue on last page of this questionnaire.

PART B — CARE IN THE LAST YEAR OF LIFE — Continued

<p>9. During the last year of life, did the person receive hospice care at home? Include only care provided by an organized hospice agency, one that gives special attention to dying persons.</p>	023	<p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No</p>
<p>10. During the last year of life, about how many times did the person see a medical doctor? Include all types of doctors such as dermatologists, psychiatrists, and ophthalmologists, as well as general practitioners and osteopaths. Do NOT count doctors seen while an overnight patient in a hospital, nursing home, or other institution. Mark (X) only one box.</p>	024	<p>0 <input type="checkbox"/> None 1 <input type="checkbox"/> 1 2 <input type="checkbox"/> 2–4 3 <input type="checkbox"/> 5–9 4 <input type="checkbox"/> 10–14 5 <input type="checkbox"/> 15–24 6 <input type="checkbox"/> 25–49 7 <input type="checkbox"/> 50 or more</p>
<p>11. During the last year of life, did the person see a psychiatrist, psychologist, or any other mental health professional about any personal, emotional, behavioral, or mental problem? Do NOT count visits while an overnight patient in a hospital, nursing home, or other institution.</p>	025	<p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No</p>
<p>12. At any time during the last year of life, was the person on a waiting list to go into a nursing home?</p>	026	<p>1 <input type="checkbox"/> Yes — Go to next question 2 <input type="checkbox"/> No — Skip to question 14</p>
<p>13. After being on the waiting list, did the person get into a nursing home before he or she died?</p>	027	<p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No</p>
<p>14. During the last year of life was the person on a waiting list to get hospice care either at home or in a facility?</p>	028	<p>1 <input type="checkbox"/> Yes — Go to next question 2 <input type="checkbox"/> No — Skip to question 16</p>
<p>15. After being on the waiting list, did the person get hospice care before he or she died?</p>	029	<p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No</p>
<p>16. During the last year of life, was the person on a waiting list to get homemaker service?</p>	030	<p>1 <input type="checkbox"/> Yes — Go to next question 2 <input type="checkbox"/> No — Skip to question 18</p>
<p>17. After being on the waiting list, did the person get homemaker service before he or she died?</p>	031	<p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No</p>
<p>18. During the last year of life was the person on a waiting list to get visiting nurse service?</p>	032	<p>1 <input type="checkbox"/> Yes — Go to next question 2 <input type="checkbox"/> No — Skip to question 20 on page 6</p>
<p>19. After being on the waiting list, did the person get visiting nurse service before he or she died?</p>	033	<p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No</p>

PART B – CARE IN THE LAST YEAR OF LIFE – Continued

As part of this survey we would like to learn about how much Medicare helps pay for health care.

034

20. Was the person covered by Medicare?

- 1 Yes – Go to next question
 2 No – Skip to question 22

21. What was the person's Medicare claim number?

035

036

Provision of this number is voluntary and failure to provide the number will not have any effect on the receipt of any benefits. The information we receive will be used only for statistical purposes. Data from this survey will be linked with data supplied by the Health Care Financing Administration. This information is collected under the authority of Section 306 of the Public Health Service Act.

Medicare claim number

□□□□ – □□□ – □□□□□□ – □□

This number may be found on the person's Medicare card which is white with a red and blue stripe. The number may also be found on the Explanation of Medicare Benefits Forms that are sent after each service used.

22. During the last year of life, what sources were used to help pay for health care in hospitals, nursing homes, physician services, or care in the home?

037

Mark (X) all that apply.

*

- 1 The person or other family members living with the person
 2 Family members not living with the person
 3 Medicare
 4 Medicaid
 5 A prepaid health maintenance organization
 6 Private health insurance

038

*

- 1 Veterans Administration
 2 Indian Health Service
 3 Other government program – Specify _____
 4 Other – Specify _____
 0 Didn't have any payments – Skip to question 24

23. Which source marked in question 22 paid MOST of the costs of health care during the last year of life?

039

 Name of source

24. What was the total amount of the person's own money that was paid for the person's medical care during the last year of life? Also include payments made by related persons living in the same household.

040

Person's OWN money. NOT total bill.

Include expenses for doctors, hospitals, nursing homes, dental, optical, medicines, and other health expenses.

Also include payments made TO Medicare and any other health insurance.

Do not include any amounts paid by or received from insurance, Medicare, or Medicaid.

If you are unsure, please make your best estimate.

Mark (X) only one box.

- 1 Less than \$200
 2 \$200 – \$499
 3 \$500 – \$999
 4 \$1,000 – \$1,999
 5 \$2,000 – \$2,999
 6 \$3,000 – \$4,999
 7 \$5,000 – \$9,999
 8 \$10,000 – \$14,999
 9 \$15,000 – \$19,999
 10 \$20,000 – \$24,999
 11 \$25,000 or more

PART B — CARE IN THE LAST YEAR OF LIFE — Continued

25. At any time during the last year of life did the person receive help from others in WALKING OR use special equipment in WALKING?

041

- 1 Yes — Go to next question
2 No — Skip to question 27

Mark "Yes" if the person couldn't walk.

(Special equipment includes canes, walkers, wheelchairs, handlebars, etc.)

26. How long was the person unable to walk or did the person receive help in WALKING or use equipment in WALKING during his or her entire life?

042

_____ Length of time

(For example, 5 years or 1 week)

27. At any time during the last year of life did the person receive help from others in EATING OR use special equipment in EATING?

043

- 1 Yes — Go to next question
2 No — Skip to question 29

28. How long did the person receive help in EATING or use special equipment in EATING during his or her entire life?

044

_____ Length of time

(For example, 5 years or 1 week)

29. At any time during the last year of life did the person receive help from others in BATHING OR use special equipment for BATHING?

045

- 1 Yes — Go to next question
2 No — Skip to question 31

30. How long did the person receive help in BATHING or use equipment in BATHING during his or her entire life?

046

_____ Length of time

(For example, 5 years or 1 week)

31. At any time during the last year of life did the person receive help from others in DRESSING OR use special equipment in DRESSING?

047

- 1 Yes — Go to next question
2 No — Skip to question 33

32. How long did the person receive help in DRESSING or use equipment in DRESSING during his or her entire life?

048

_____ Length of time

(For example, 5 years or 1 week)

33. At any time during the last year of life did the person receive help from others in using the TOILET OR use special equipment in using the TOILET?

049

- 1 Yes — Go to next question
2 No — Skip to question 35 on page 8

34. How long did the person receive help in using the TOILET or use equipment in using the TOILET during his or her entire life?

050

_____ Length of time

(For example, 5 years or 1 week)

PART B — CARE IN THE LAST YEAR OF LIFE — Continued

<p>35. For how much of the last year of life was the person in a nursing home or other health facility or any other type of institution?</p> <p><i>Mark (X) only one box.</i></p>	<p>051</p> <p>0 <input type="checkbox"/> None — <i>Go to next question</i></p> <p>1 <input type="checkbox"/> At least one night but less than half of the last year — <i>Go to next question</i></p> <p>2 <input type="checkbox"/> At least half but not all of the last year — <i>Go to next question</i></p> <p>3 <input type="checkbox"/> All of the last year — <i>Skip to question 39</i></p>
<p>36. During the last year of life, did the person receive help AT HOME from other persons in walking, eating, bathing, dressing, or using the toilet?</p>	<p>052</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No</p>
<p>37. During the last year of life, did anyone help the person AT HOME in giving medicines, pills, shots, injections, in changing bandages, or by providing nursing care?</p>	<p>053</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No</p>
<p><i>If you marked No in both questions 36 AND 37, skip to question 39.</i></p> <p>38. Who helped the person AT HOME during the last year of life?</p> <p><i>Mark (X) all that apply.</i></p>	<p>055</p> <p>* 1 <input type="checkbox"/> Husband or wife</p> <p>2 <input type="checkbox"/> Son</p> <p>3 <input type="checkbox"/> Daughter</p> <p>4 <input type="checkbox"/> Other relative — What relation? <input checked="" type="checkbox"/> _____</p> <p>_____</p> <p>056</p> <p>* 5 <input type="checkbox"/> Neighbor or friend</p> <p>6 <input type="checkbox"/> Visiting nurse</p> <p>7 <input type="checkbox"/> Visiting homemaker</p> <p>8 <input type="checkbox"/> Other — <i>Specify</i> _____</p> <p>_____</p>
<p>39. During the last year of life, how often did the person have trouble understanding where he or she was?</p> <p><i>Mark (X) only one box.</i></p>	<p>057</p> <p>1 <input type="checkbox"/> All or most of the time</p> <p>2 <input type="checkbox"/> Some of the time</p> <p>3 <input type="checkbox"/> Only in last few hours or days before death</p> <p>4 <input type="checkbox"/> Never or hardly ever</p>
<p>40. During the last year of life, how often did the person have trouble remembering what year it was?</p> <p><i>Mark (X) only one box.</i></p>	<p>058</p> <p>1 <input type="checkbox"/> All or most of the time</p> <p>2 <input type="checkbox"/> Some of the time</p> <p>3 <input type="checkbox"/> Only in last few hours or days before death</p> <p>4 <input type="checkbox"/> Never or hardly ever</p>
<p>41. During the last year of life, how often did the person have trouble recognizing family members or good friends?</p> <p><i>Mark (X) only one box.</i></p>	<p>059</p> <p>1 <input type="checkbox"/> All or most of the time</p> <p>2 <input type="checkbox"/> Some of the time</p> <p>3 <input type="checkbox"/> Only in last few hours or days before death</p> <p>4 <input type="checkbox"/> Never or hardly ever</p>
<p>42. Did the person ever sign a paper stating NOT to use life-sustaining equipment or procedures if the person was definitely dying? This paper is sometimes called a "living will."</p>	<p>060</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No</p>

PART B — CARE IN THE LAST YEAR OF LIFE — Continued

43. During the LAST THREE YEARS OF LIFE, did anyone have any problems in finding a nursing home for the person or getting the person into a nursing home?

061

- 1 Yes — Very serious problem
- 2 Yes — Somewhat serious problem
- 3 No — Not a problem or not applicable

44. During the LAST YEAR OF LIFE, did anyone have any problems in getting help to care for the person at home?

062

- 1 Yes — Very serious problem
- 2 Yes — Somewhat serious problem
- 3 No — Not a problem or not applicable

45. During the last year of life, did anyone have any problems in paying the medical bills for the person?

063

- 1 Yes — Very serious problem
- 2 Yes — Somewhat serious problem
- 3 No — Not a problem or not applicable

46. During the last year of life, did anyone have any problems in finding and getting treatment from a doctor for the person?

064

- 1 Yes — Very serious problem
- 2 Yes — Somewhat serious problem
- 3 No — Not a problem or not applicable

Continue with Part C on the next page.

PART C — LIFE STYLE AND HEALTH

<p>1. AT ANY TIME IN THE PERSON'S LIFE, did he or she ever have high blood pressure (hypertension)?</p>	065	<p>1 <input type="checkbox"/> Yes — Go to next question 2 <input type="checkbox"/> No — Skip to question 5</p>
<p>2. How long before death was the high blood pressure (hypertension) first noticed? (For example, 3 years or 2 weeks)</p>	066	<p>_____ Time before death</p>
<p>3. Did a doctor prescribe medicine for the high blood pressure?</p>	067	<p>1 <input type="checkbox"/> Yes — Go to next question 2 <input type="checkbox"/> No — Skip to question 5</p>
<p>4. On the average over the time prescribed, did the person take the medicine regularly? (If more than one medicine was prescribed, did the person take all or most of them regularly?)</p>	068	<p>1 <input type="checkbox"/> Very regularly 2 <input type="checkbox"/> Not very regularly 3 <input type="checkbox"/> Hardly at all or never</p>
<p>5. At any time in the person's life, did he or she ever have a heart attack?</p>	069	<p>1 <input type="checkbox"/> Yes — Go to next question 2 <input type="checkbox"/> No — Skip to question 7</p>
<p>6. How long before death did the person have the FIRST heart attack? (For example, 3 years or 2 weeks)</p>	070	<p>_____ Time before death</p>
<p>7. At any time in the person's life, did he or she ever have angina pectoris?</p>	071	<p>1 <input type="checkbox"/> Yes — Go to next question 2 <input type="checkbox"/> No — Skip to question 9</p>
<p>8. How long before death was the angina pectoris first noticed? (For example, 3 years or 2 weeks)</p>	072	<p>_____ Time before death</p>
<p>9. At any time in his or her life, did the person have a stroke in which any resulting conditions (such as paralysis, loss of vision or speech) lasted AT LEAST ONE DAY OR LONGER?</p>	073	<p>1 <input type="checkbox"/> Yes — Go to next question 2 <input type="checkbox"/> No — Skip to question 11</p>
<p>10. How old was the person when he or she had the first stroke in which there were resulting conditions lasting at least one day? If not sure, give approximate age.</p>	074	<p>_____ Age in years</p>
<p>11. AT ANY TIME IN THE PERSON'S LIFE, did a doctor say that the person had Alzheimer's disease, chronic brain syndrome, dementia, senility, or any other serious memory impairment?</p>	075	<p>1 <input type="checkbox"/> Yes — Go to next question 2 <input type="checkbox"/> No — Skip to question 13 on page 11</p>
<p>12. How long before death was this diagnosis first made? (For example, 3 years or 2 months)</p>	076	<p>_____ Time before death</p>

PART C — LIFE STYLE AND HEALTH — Continued

13. At any time in the person's life, did he or she have any OTHER mental, nervous, or emotional health problem?

077

- 1 Yes — Go to next question
2 No — Skip to question 15

14. How long before death was the other mental, nervous, or emotional health problem first noticed?

078

(For example, 3 years or 2 months)

_____ Time before death

15. At any time during the person's life, did he or she have diabetes?

079

- 1 Yes — Go to next question
2 No — Skip to question 17

16. How long before death was the diabetes first noticed?

080

(For example, 3 years or 2 months)

_____ Time before death

17. Was cancer the main condition leading to death?

081

- 1 Yes — Go to next question
2 No — Skip to question 19

18. How long before death was this cancer first noticed?

082

(For example, 3 years or 2 months)

_____ — Skip to question 21
Time before death

19. At any time during the person's life, did he or she have cancer of any kind, except skin cancer?

083

- 1 Yes — Go to next question
2 No — Skip to question 21

20. How long before death was cancer, except skin cancer, first noticed?

084

(For example, 3 years or 2 months)

_____ Time before death

21. At any time during the person's life, did he or she have asthma ?

085

- 1 Yes — Go to next question
2 No — Skip to question 23

22. How long before death was the asthma first noticed?

086

(For example, 3 years or 2 months)

_____ Time before death

23. At any time during the person's life, did he or she have any other lung condition such as emphysema or bronchitis lasting 3 months or longer?

087

- 1 Yes — Go to next question
2 No — Skip to question 25 on page 12

24. How long before death was the first lung condition first noticed?

088

(For example, 3 years or 2 months)

_____ Time before death

PART C — LIFE STYLE AND HEALTH — Continued

<p>25. At any time in the person's life, did he or she have cirrhosis of the liver ?</p>	<p>089</p>	<p>1 <input type="checkbox"/> Yes — Go to next question 2 <input type="checkbox"/> No — Skip to question 27</p>
<p>26. How long before death was the cirrhosis first noticed? (For example, 3 years or 2 months)</p>	<p>090</p>	<p>_____ Time before death</p>
<p>27. Was there ever a time in the person's life that he or she was thought to be extremely near to death but lived on?</p>	<p>091</p>	<p>1 <input type="checkbox"/> Yes — Go to next question 2 <input type="checkbox"/> No — Skip to question 29</p>
<p>28. When was this time in the person's life when he or she was thought to be extremely near to death but lived on? (If there was more than one time, please answer for the first time.) Mark (X) only one box.</p>	<p>092</p>	<p>1 <input type="checkbox"/> Less than 3 months before actual death 2 <input type="checkbox"/> 3 months to less than a year before death 3 <input type="checkbox"/> 1 year to less than 5 years before death 4 <input type="checkbox"/> 5 years or more before death</p>
<p>29. Where did the person die? Mark (X) only one box.</p>	<p>093</p>	<p>1 <input type="checkbox"/> In a hospital emergency room 2 <input type="checkbox"/> In a hospital, not in emergency room 3 <input type="checkbox"/> On the way to a hospital 4 <input type="checkbox"/> In a nursing home or personal care home 5 <input type="checkbox"/> In his or her own home 6 <input type="checkbox"/> In some other place — Specify ↙ _____</p>
<p>30. At any time during the hour before death were you with the person?</p>	<p>094</p>	<p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No</p>
<p>31. What was the person doing an hour before death? Mark (X) all that apply.</p>	<p>095</p>	<p>* 1 <input type="checkbox"/> Confined to bed or chair because of illness or injury 2 <input type="checkbox"/> Working 3 <input type="checkbox"/> Quiet recreation such as watching TV or playing cards 4 <input type="checkbox"/> Active recreation such as yard work, exercise or sports 5 <input type="checkbox"/> Sleeping 6 <input type="checkbox"/> Other — Specify ↙ _____</p>
<p>32. Within the hour before death, did the person start having a new or sharply increased problem such as chest pain, difficulty breathing, or fainting?</p>	<p>096</p>	<p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No</p>

PART C — LIFE STYLE AND HEALTH — Continued

IF THE PERSON WAS A MALE, SKIP TO QUESTION 42.

33. Did she **EVER** regularly take birth control pills?

098

- 1 Yes — Go to next question
2 No — Skip to question 36

34. Altogether, about how long did she take birth control pills?

099

- 1 Less than one year
2 1 year but less than 5 years
3 5 years but less than 10 years
4 10 years or longer

35. At what age did she start taking birth control pills?

100

If not sure, give approximate age.

_____ Age in years

36. How many **LIVE BIRTHS** did she ever have? Please include children who died very young.

101

_____ Number of live births

37. Did she ever have a hysterectomy?

102

(An operation to remove the uterus.)

- 1 Yes — Go to next question
2 No — Skip to question 40

38. How old was she when she had the hysterectomy?

103

If unsure, give approximate age.

_____ Age in years

39. Before the hysterectomy, had her menstrual periods already ended due to menopause or the "change of life"?

104

- 1 Yes — Skip to question 41
2 No — Skip to question 42

40. Had her menstrual periods ever ended due to menopause or the "change of life"?

105

- 1 Yes — Go to next question
2 No — Skip to question 42

41. How old was she when her menstrual periods ended?

106

If unsure, give approximate age.

_____ Age in years

ANSWER FOR BOTH MALE AND FEMALE

107

42. Did the person ever have an operation to be sterilized?

(For males, a vasectomy. For females, "tubes tied" or tubal ligation.)

- 1 Yes — Go to next question
2 No — Skip to question 44 on page 14

43. How old was the person when he or she had an operation to be sterilized?

108

If unsure, give approximate age.

_____ Age in years

PART C — LIFE STYLE AND HEALTH — Continued

In these next questions, we are interested in the person's usual practice, not in any possible recent change because of a health problem.

DURING MOST OF HIS OR HER ADULT LIFE, on the average, how often did the person usually eat the following foods —

44. Red meat, such as beef, pork, lamb, or hamburger?

109

- 1 Every day.
- 2 3 to 6 times a week
- 3 1 or 2 times a week
- 4 1 to 3 times a month
- 5 Less than once a month
- 6 Never

Mark (X) only one box.

45. Eggs or dairy products, such as milk, cheese, or butter?

110

- 1 Every day
- 2 3 to 6 times a week
- 3 1 or 2 times a week
- 4 1 to 3 times a month
- 5 Less than once a month
- 6 Never

Mark (X) only one box.

46. Fruit?

111

- 1 Every day
- 2 3 to 6 times a week
- 3 1 or 2 times a week
- 4 1 to 3 times a month
- 5 Less than once a month
- 6 Never

Mark (X) only one box.

47. Vegetables?

112

- 1 Every day
- 2 3 to 6 times a week
- 3 1 or 2 times a week
- 4 1 to 3 times a month
- 5 Less than once a month
- 6 Never

Mark (X) only one box.

48. Foods prepared by salt-curing or smoking, such as bacon, hot dogs, or smoked fish?

113

- 1 Every day
- 2 3 to 6 times a week
- 3 1 or 2 times a week
- 4 1 to 3 times a month
- 5 Less than once a month
- 6 Never

Mark (X) only one box.

49. During MOST of his or her adult life, was the person overweight, underweight, or just about right?

114

- 1 Very overweight
- 2 Somewhat overweight
- 3 Only a little overweight
- 4 Underweight
- 5 About right

Mark (X) only one box.

50. On the average, approximately what was the person's usual adult weight?

115

_____ Pounds

51. What was the person's adult height?

116

_____ Feet

Enter both feet and inches, such as "5 feet and 6 inches." If no inches, enter "0."

AND

117

_____ Inches

PART C — LIFE STYLE AND HEALTH — Continued

<p>52. Did the person smoke at least 100 cigarettes in his or her entire life? (There are usually 20 or 25 cigarettes in a pack.)</p>	<p>118</p>	<p>1 <input type="checkbox"/> Yes — Go to next question 2 <input type="checkbox"/> No — Skip to question 57</p>
<p>53. How long did he or she smoke cigarettes regularly? Enter years or mark (X) a box.</p>	<p>119</p>	<p>_____ Years } Go to next question x <input type="checkbox"/> Less than 1 year 0 <input type="checkbox"/> Never smoked regularly — Skip to question 55</p>
<p>54. During the period he or she smoked most, on the average, about how many cigarettes a day did the person usually smoke? Mark (X) only one box.</p>	<p>120</p>	<p>1 <input type="checkbox"/> Less than 5 cigarettes a day 2 <input type="checkbox"/> 5—14 a day 3 <input type="checkbox"/> 15—24 a day 4 <input type="checkbox"/> 25—34 a day 5 <input type="checkbox"/> 35—44 a day 6 <input type="checkbox"/> 45 or more a day</p>
<p>55. Did the person stop smoking and not start again?</p>	<p>121</p>	<p>1 <input type="checkbox"/> Yes — Go to next question 2 <input type="checkbox"/> No — Skip to question 57</p>
<p>56. How long before death did the person stop smoking? (For example: 3 years or 2 months)</p>	<p>122</p>	<p>_____ Time before death</p>
<p>57. Did the person ever regularly use chewing tobacco?</p>	<p>123</p>	<p>1 <input type="checkbox"/> Yes — Go to next question 2 <input type="checkbox"/> No — Skip to question 60</p>
<p>58. How long did he or she regularly use chewing tobacco? Enter years or mark (X) the box.</p>	<p>124</p>	<p>_____ Years x <input type="checkbox"/> Less than 1 year</p>
<p>59. When he or she was regularly using chewing tobacco, on the average, how often did the person use it? Mark (X) only one box.</p>	<p>125</p>	<p>1 <input type="checkbox"/> 5 or more times a day 2 <input type="checkbox"/> 3—4 times a day 3 <input type="checkbox"/> 1—2 times a day 4 <input type="checkbox"/> 3—6 times a week 5 <input type="checkbox"/> 1 or 2 times a week 6 <input type="checkbox"/> 1 to 3 times a month 7 <input type="checkbox"/> Less than once a month</p>
<p>60. Did the person ever regularly use snuff?</p>	<p>126</p>	<p>1 <input type="checkbox"/> Yes — Go to next question 2 <input type="checkbox"/> No — Skip to question 63 on page 16</p>
<p>61. How long did he or she regularly use snuff? Enter years or mark (X) the box.</p>	<p>127</p>	<p>_____ Years x <input type="checkbox"/> Less than 1 year</p>
<p>62. When he or she was regularly using snuff, on the average, how often did the person use it? Mark (X) only one box.</p>	<p>128</p>	<p>1 <input type="checkbox"/> 5 or more times a day 2 <input type="checkbox"/> 3—4 times a day 3 <input type="checkbox"/> 1—2 times a day 4 <input type="checkbox"/> 3—6 times a week 5 <input type="checkbox"/> 1 or 2 times a week 6 <input type="checkbox"/> 1 to 3 times a month 7 <input type="checkbox"/> Less than once a month</p>

PART C — LIFE STYLE AND HEALTH — Continued

63. In the person's entire adult life, did he or she have at least 12 drinks of any kind of alcoholic beverage, such as beer, wine, or liquor?

129

- 1 Yes — Go to next question
2 No — Skip to question 66

64. On the average, during adult life, how often did he or she drink any alcoholic beverages, such as beer, wine, or liquor?

130

Mark (X) only one box.

- 1 Every day
2 3 to 6 times a week
3 1 or 2 times a week
4 1 to 3 times a month
5 Less than once a month

65. On the days that the person drank, how many drinks did he or she have on the average, per day?

131

Mark (X) only one box.

- 1 Twelve or more
2 Seven to eleven
3 Five or six
4 Three or four
5 Two
6 One

66. Over the last 10 years (and not counting the last illness), did the person exercise vigorously at least three times a week, for at least 20 minutes each time?

132

(For example: running, swimming, bicycling, walking briskly, aerobic exercise, etc.)

Mark (X) only one box.

- 1 Very regularly
2 Not very regularly
3 Hardly at all or never

PART D — CHARACTERISTICS OF PERSON

1. Did the person EVER work at a paying job or a business full or part time?

133

- 1 Yes — Go to next question
 2 No — Skip to question 8

2. Of all the PAID jobs or businesses the person ever had, what KIND OF WORK did he or she do the longest? (For example, electrical engineer, stock clerk, typist, farmer, in Armed Forces, etc.)

134

3. For how many years did the person do this kind of work?

135

Mark (X) only one box.

- 1 Less than one year
 2 1 to less than 5 years
 3 5 to less than 10 years
 4 10 to less than 20 years
 5 20 to less than 30 years
 6 30 to less than 40 years
 7 40 years or more

4. In this occupation, what KIND OF BUSINESS OR INDUSTRY did he or she work in the longest? Describe the activity at the location where employed. (For example: TV and radio manufacturing, retail shoe store, State Labor Department, farm, Armed Forces, etc.)

136

5. Was the person employed at a paying job or business up until the time he or she died?

137

- 1 Yes — Skip to question 8
 2 No — Go to next question

6. Why did the person stop working?

138

Mark (X) only one box.

- 1 Because of a health problem or disability
 2 Because of loss of job
 3 Normal retirement
 4 Other reason — Specify

7. How long before death was the last time the person worked at a paying job or business (full or part time)?

139

(For example: 3 years or 2 months)

Time before death

8. Did the person's husband or wife ever work at a paying job or business full or part time?

140

If married more than once, answer for most recent husband or wife.

- 1 Yes — Go to next question
 2 No
 3 Never married } Skip to question 11 on page 18

9. Of all the PAID jobs or businesses the person's husband or wife ever had, what KIND OF WORK did the husband or wife do the longest? (For example, electrical engineer, stock clerk, typist, farmer, in Armed Forces, etc.)

141

10. In this occupation, what KIND OF BUSINESS OR INDUSTRY did the husband or wife work in the longest? Describe the activity at the location where employed. (For example, TV and radio manufacturing, retail shoe store, State Labor Department, farm, Armed Forces, etc.)

142

PART D — CHARACTERISTICS OF PERSON — Continued

11. What was the size of the family during most of 1985? (Include the person and all of his or her relatives living in the same household.)

143

Mark (X) only one box.

- 0 Person lived in nursing home, other health facility, or other institution during most of 1985
- 1 One (Person either lived alone or with unrelated persons)
- 2 Two
- 3 Three
- 4 Four
- 5 Five
- 6 Six
- 7 Seven
- 8 Eight
- 9 Nine or more

12. What was the family's income in 1985?

144

(Please include the person's income and the income of all other related persons living in the same household as the person. Include money from jobs, social security, retirement income, unemployment payments, public assistance, etc. Also include income from interest, dividends, net income from business, farm, or rent, and any other money income received.)

Mark (X) only one box.

- 1 Less than \$5,000
- 2 \$5,000 — \$6,999
- 3 \$7,000 — \$8,999
- 4 \$9,000 — \$10,999
- 5 \$11,000 — \$12,999
- 6 \$13,000 — \$14,999
- 7 \$15,000 — \$16,999
- 8 \$17,000 — \$18,999
- 9 \$19,000 — \$21,999
- 10 \$22,000 — \$24,999
- 11 \$25,000 and over

13. Was the person ever on active duty in the U.S. Armed Forces?

145

NOTE — Mark "No" if all of the active duty service was related to training in the National Guard or military reserve.

- 1 Yes — Go to next question
- 2 No — Skip to question 15

14. At the time of death, was the person on full-time active duty with the Armed Forces?

146

- 1 Yes
- 2 No

15. Which category BEST represents the person's race?

147

Mark (X) only one box.

- 1 American Indian, Aleut, or Eskimo
- 2 Asian or Pacific Islander
- 3 Black
- 4 White

16. Was this person of Spanish or Hispanic origin or descent?

150

- 1 Yes
- 2 No

PART D — CHARACTERISTICS OF PERSON — Continued

17. Who did the person live with at the time of death?
(If the person was living in an institution at the time of death, who did he or she live with BEFORE entering the institution?)

151

- 1 Lived alone — *Go to next question*
 2 Lived with other persons (List relationship for each **other** person below, for example, husband/wife, son, friend, etc.)

Person	Relationship
1	
2	
3	
4	
5	
6	
7	
8	

If more room is needed to list additional persons, continue on the last page of this questionnaire.

152
153
154
155
156
157
158
159

18. What was the highest grade or year of regular school the person ever completed?

160

Mark (X) only one box.

- 1 Less than 5 years
 2 5–7 years
 3 8 years
 4 9–11 years
 5 High school graduate
 6 1–3 years of college
 7 4 years of college or more

19. At the time of his or her death, what was the marital status of the person?

161

- 1 Married — *Skip to question 21*
 2 Widowed — *Go to next question*
 3 Divorced } *Skip to question 21*
 4 Separated }
 5 Never married — *Skip to question 26 on page 20*

20. About how long before the person's death did the person's husband or wife die?

162

(For example: 3 years or 2 months)

_____ Time before person's death

21. Counting all marriages which the person may have had, for how many years ALTOGETHER was he or she married?

163

Enter number or mark (X) the box.

- _____ Years
 x Less than 1 year

22. How many different persons was he or she ever married to during his or her entire life?

164

_____ Number of different husbands or wives

23. What was the highest grade or year of regular school completed by the person's husband or wife?

165

If the person was married more than once, answer for the most recent husband or wife.

Mark (X) only one box.

- 1 Less than 5 years
 2 5–7 years
 3 8 years
 4 9–11 years
 5 High school graduate
 6 1–3 years of college
 7 4 years of college or more

PART D — CHARACTERISTICS OF PERSON — Continued

24. While the person was married, did his or her husband or wife smoke at least 100 cigarettes?

166

- 1 Yes — Go to next question
2 No — Skip to question 26

If the person was married more than once and any of the husbands or wives smoked at least 100 cigarettes, mark "Yes".

25. On the average, how many cigarettes a day did the person's husband or wife smoke?

167

- 1 Less than 5 cigarettes a day
2 5—14 a day
3 15—24 a day
4 25—34 a day
5 35—44 a day
6 45 or more a day

If the person was married more than once, answer for the most recent husband or wife who smoked.

26. In what year was the person's natural father born?

168

If unsure, please give approximate year.

--	--	--	--

Year of father's birth

27. If the person's natural father has died, how old was the father when the father died?

169

Give age or mark (X) the box.

_____ Father's age at death
x Still living

28. In what year was the person's natural mother born?

170

If unsure, please give approximate year.

--	--	--	--

Year of mother's birth

29. If the person's natural mother has died, how old was the mother when the mother died?

171

Give age or mark (X) the box.

_____ Mother's age at death
x Still living

30. Did the person's natural father ever have a heart attack?

172

- 1 Yes — Go to next question
2 No — Skip to question 32

31. About how old was the person's natural father when he had his first heart attack?

173

If unsure, please give approximate age.

_____ Age of father

32. Did the person's natural mother ever have a heart attack?

174

- 1 Yes — Go to next question
2 No — Skip to question 34 on page 21

33. About how old was the person's natural mother when she had her first heart attack?

175

If unsure, please give approximate age.

_____ Age of mother

PART D — CHARACTERISTICS OF PERSON — Continued

34. How many brothers who lived to be 25 years old or older did the person have? 176
 (Do not include half, step, or adoptive brothers.) _____ Number of brothers — *Go to next question*
 Enter number or mark (X) the box. None — *Skip to question 37*

35. How many of the person's brothers ever had a heart attack? 177
 (Count only brothers who lived to be at least 25 years old.) _____ Number who had a heart attack — *Go to next question*
 Enter number or mark (X) the box. None — *Skip to question 37*

36. How old were these brothers when they had a heart attack?
 For each brother who had a heart attack, enter that brother's age when he had the first heart attack. 178 _____ Brother's age at time of heart attack
 If unsure, give approximate ages. 179 _____ Brother's age at time of heart attack
180 _____ Brother's age at time of heart attack
181 _____ Brother's age at time of heart attack
182 _____ Brother's age at time of heart attack
183 _____ Brother's age at time of heart attack

37. How many sisters who lived to be 25 years old or older did the person have? 184
 (Do not include half, step, or adoptive sisters.) _____ Number of sisters — *Go to next question*
 Enter number or mark (X) the box. None — *Skip to question 40 on page 22*

38. How many of the person's sisters ever had a heart attack? 185
 (Count only sisters who lived to be at least 25 years old.) _____ Number who had a heart attack — *Go to next question*
 Enter number or mark (X) the box. None — *Skip to question 40 on page 22*

39. How old were these sisters when they had a heart attack?
 For each sister who had a heart attack, enter that sister's age when she had the first heart attack. 186 _____ Sister's age at time of heart attack
 If unsure, give approximate ages. 187 _____ Sister's age at time of heart attack
188 _____ Sister's age at time of heart attack
189 _____ Sister's age at time of heart attack
190 _____ Sister's age at time of heart attack
191 _____ Sister's age at time of heart attack

PART D — CHARACTERISTICS OF PERSON — Continued

40. At the time of death, what was the total value of things (including a home if any) owned by the person (and husband or wife)?

192

Subtract any debts and mortgages. Include cash in bank accounts, stocks, bonds, cars, jewelry, business interests, etc.


If unsure, please make your best estimate.

Mark (X) only one box.

- 0 Zero net worth (or loss)
- 1 \$1 — \$4,999
- 2 \$5,000 — \$24,999
- 3 \$25,000 — \$49,999
- 4 \$50,000 — \$99,999
- 5 \$100,000 — \$249,999
- 6 \$250,000 — \$499,999
- 7 \$500,000 or more

41. Is there anyone else who might be able to add to the information you gave on this questionnaire?

Yes — **What is his or her name, address, and telephone number?**

No — *Go to next question* 

Name _____

Address (Number and street) _____

City or Post Office _____

State _____ ZIP Code _____

Area code _____ Telephone number _____

No telephone

42. Sometimes particular questions are not clear to the person answering them. Would you please give us your name and telephone number so that we can call you in case we have some questions?

Your name _____

Area code _____ Telephone number _____

No telephone

Please go to the next page, read and complete the authorization. 

- 193
- 194
- 195
- 196
- 197

**AUTHORIZATION TO OBTAIN INFORMATION
FROM MEDICAL RECORDS**

I hereby give my consent for hospitals, nursing homes, and other medical sources that maintain records on the person named below to provide the required information to the National Center for Health Statistics through the U.S. Bureau of the Census. I understand that the National Center for Health Statistics will use this information only for statistical purposes and no information which identifies me, the person named below, or the medical source will ever be released or published.

(Today's date)

(Your signature)

(Relationship to the deceased)

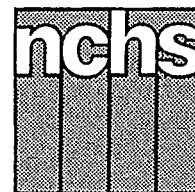
(Name of the deceased. Please print)

This authorization expires one year from date of signature.

**Please return this entire questionnaire to the
Bureau of the Census in the envelope provided.**

THANK YOU VERY MUCH FOR YOUR COOPERATION.

Reviews of New Reports



From the CENTERS FOR DISEASE CONTROL AND PREVENTION/National Center for Health Statistics

The National Mortality Followback Survey: 1986 Summary for the United States

Series 20, No. 19
(PHS) 92-1856

Author: Seeman, I.

For information contact:

Kathi Brannan
Scientific and Technical Information Branch
6525 Belcrest Road, Rm. 1064
Hyattsville, MD 20782

Tel: (301) 436-8500

The National Center for Health Statistics has just released a report that provides national estimates of the incidence of significant characteristics of adults who died in the United States in 1986. The report, "National Mortality Followback Survey: 1986 Summary, United States" presents data on the use of health services, disabilities, lifestyle practices that may affect health and mortality, and socioeconomic circumstances for the adults that were studied.

Selective information from this survey has been weighted and is presented in 81 comprehensive tables. The data have been arranged into three categories: health care in the last year of life, lifestyle and health, and socioeconomic characteristics of decedents.

According to the section on health care, some institutional care in the last year of life—in either a hospital or nursing home—was required for 81.1 percent of the decedents. Medicare covered 72.9 percent of all decedents and 92.3 percent of those age 65 and over. Even with coverage, about 12 percent of the elderly had somewhat serious to very serious problems with payments of medical bills.

In the section on lifestyle, the incidence of heart attacks at some time during a lifetime was reported for 29.2 percent of the decedents; whereas, the incidence of Alzheimer's disease and other memory impairments was 11.2 percent. According to the study, approximately 55.6 percent of the decedents smoked at least 100 cigarettes and 71.9 percent drank at least 12 alcoholic drinks in a lifetime. Approximately 16.9 percent of the decedents had exercised vigorously at least three times a week for at least 20 minutes each time, while 66.4 percent of the decedents hardly or never exercised.

According to the section on socioeconomic characteristics, 27.2 percent of the decedents lived alone;

for women it was 35.9 percent and for men 19.1 percent. Educational attainment was at the elementary school level for 32.5 percent of the decedents; the high school level for 42.1 percent; and the college level for 17.7 percent. Approximately 86.2 percent of the decedents worked at some time during their lifetime, and 13.1 percent of the decedents worked until the time of death.

The data presented in this report are from the fifth survey in a series of National Mortality Followback Surveys (NMFS) conducted by NCHS. The 1986 NMFS data were collected from 16,598 informants; 81 percent of whom were the next of kin or another close relative of the decedent. Information about the decedent secured from informants was supplemented by data collected from hospitals, nursing homes, and other health care facilities in which the decedent spent at least one night during the last year of life.

Copies of the report can be purchased from the U.S. Government Printing Office by completing the order form on the back of this release.

*U.S. Government Printing Office: 1993 — 342-327/80006



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Public Health Service

Centers for Disease Control and Prevention
National Center for Health Statistics



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For answers to questions about this report or for a list of reports published in these series, contact:

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