

How to Get to the Data Service for Epidemiological Research Announcement Page

Access the Social Security Online Website at: <http://www.socialsecurity.gov/>

1. Scroll to the bottom and click on the Site Map icon
2. Scroll down left side of the Site Map page until you see “Office of Policy” and then click on the Office of Policy Website at: [about the Office of Policy](#)
3. At the top of the page, click on “about the Office of Policy”
4. At the “About Us” Screen, click on “Major Responsibilities and Projects”
5. At the “Major Responsibilities and Projects” Screen, scroll down to bold heading entitled, “Data Service for Epidemiological Research.” Below in the text of this heading is the a link to more information on “Service to Epidemiological Researchers to Provide Vital Status Data on Subjects of Health Research.” Click on this website and it will take you to the announcement entitled, “Announcement of Service to Epidemiological Researchers to Provide Vital Status Data on Subjects of Health Research” (# 4190-29P).
6. The announcement describes the entire procedure required by health researchers to request and obtain vital status information, and includes the application and links to the data protection plan, and confidentiality statement.



Social Security Online

The Official Website of the U.S. Social Security Administration



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www.socialsecurity.gov

Monday Oct 29, 2007 06:55:41 Last updated October 24, 2007 9:58 AM

New rules for getting a Social Security number and card



What you can do online

[Apply for benefits](#)

[Replace your lost, stolen or damaged Medicare card](#)

[Request a Proof of Income letter](#)

[Change address/phone number](#)

[Find a Social Security office](#)

[More online services....](#)

News

[Social Security announces the 2008 Cost-of-Living Adjustment](#)

[First Baby Boomer files for retirement benefits online](#)

[Social Security Administration attacks disability backlog](#)

[Commissioner Astrue Extends Social](#)

The first Baby Boomer has filed for retirement online.

You can too.



Show someone you love how much you care

Your Social Security records

[Your number & card](#) | [Your Statement](#)

Retirement

[Plan your retirement](#) | [Calculate your benefits](#)
[Qualify & apply](#) | [Already receiving benefits](#)

Medicare

[Medicare Prescription Drug Plan](#) | [Other Medicare information](#)

Disability & SSI

[Qualify & apply](#) | [Already receiving benefits](#)
[Ticket to Work](#) | [Adults disabled before age 22](#)
[More disability information](#) | [SSI for people 65 and older](#)

Widows, widowers & other survivors

[Report a death](#) | [Qualify & apply](#)
[Already receiving benefits](#)

Get help with your situation

[Marriage, divorce, and name changes](#)
[Birth of a child](#) | [Death in the family](#)
[Disagree with our decision?](#) | [More situations...](#)

[Business Services Online](#)



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Frequently Asked Questions

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Information for:

[The Press](#)

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Useful links

[Benefit Eligibility Screening Tool \(BEST\)](#)

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[Our program rules](#)

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-- Other Useful Links --

62:65:67 Full retirement age is increasing

eNews Check out our latest electronic newsletter

[Security's Quick
Disability
Determination
Nationwide](#)

[Social Security
delivers the
most popular
baby names for
2006](#)

[Social Security
Trustees
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Annual Report](#)

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[Mission](#) | [FOIA](#) | [Regulations.gov](#) |
[No Fear Act Data](#) | This is a U.S. Government computer system
subject to Federal law

Step 1

Social Security Online **Site Map****An Index of Social Security Online**

Instructions

Select A-Z below to get close to your topic or just scroll through the list of topics on this page.

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[R](#) [S](#) [T](#) [U](#) [V](#) [W](#) [X](#) [Y](#) [Z](#)

Actuarial Information

The Office of the Actuary prepares reports on the financial outlook of Social Security and historical data on numbers of beneficiaries and average benefits.

- [Publications](#)
 - [The Trustees Report](#)--Financial Outlook for Social Security
 - Actuarial [Studies](#) and [Notes](#)
- [Estimate your benefit](#) with one of our calculators
- [Automatic Increases](#) --COLAs and Wage-Indexed Amounts
- [Program Data](#)
 - Trust Fund [Financial Data](#) --historical data on trust fund operations and investments
 - [Beneficiary Data](#) --historical data on numbers of beneficiaries and average benefits
- [Actuaries at SSA](#)

Advisory Board

[The Social Security Advisory Board](#) is an independent, bipartisan Board created by Congress and appointed by the President and the Congress to advise the President, the Congress, and the Commissioner of Social Security on matters related to the Social Security and Supplemental Security Income programs.

Appeals

Information on how to appeal a decision from Social Security

[Frequently Asked Questions About SSA's Appeals process](#)

- [Publications on the Appeals Process](#)
- [Selected Appeals Forms](#)
- [Office of Disability Adjudication and Review](#)

Applying for Benefits

- [How To Apply For Social Security Retirement Benefits](#)
- [How To Apply For Social Security Disability](#)

	<ul style="list-style-type: none"> Benefits Apply for Retirement/Spouse`s Benefits Online Apply for Disability Benefits Online 	
Applying for a Social Security Number	How to Apply For a Replacement Social Security Card	
Baby Names	See the most popular given names by gender and year of birth .	What are the most popular names given to newborns?
Benefits	<ul style="list-style-type: none"> Benefit Publications - a complete list of all publications Lista De Publicaciones En Español (Spanish Publications) Medicare Information FAX Catalog -- Publications about benefits by FAX Social Security Disability Benefits The Social Security Handbook -- A comprehensive guide to all of Social Security`s benefit programs Latest COLA and how it was calculated A Fact Sheet on the latest COLA Compute your own benefit with either our Quick Calculator or Detailed Calculator Benefits Planner 	
Budget Documents	<ul style="list-style-type: none"> Operational Finances — SSA`s Performance and Accountability Report for Fiscal Year (FY) 2006 The FY 2007 Budget Proposal for the Social Security Administration Fiscal Year 2007 Annual Performance Plan 	
Change of Address	<ul style="list-style-type: none"> How to change your address Change your address or phone number online Request or change direct deposit of checks 	Frequently Asked Questions about Changing Your Address
Checks	Schedule of Payments	
Commissioner of Social Security	The Commissioner of the Social Security Administration is Michael J. Astrue .	
Computing Your Benefit	<ul style="list-style-type: none"> The Social Security Statement - A statement of your lifetime earnings and an estimate of your benefits. Estimate your benefit with one of our calculators How Your Retirement Benefit is Figured - A 	

	<p>publication on how your benefit is computed</p> <ul style="list-style-type: none"> • Formula for computing the primary insurance amount (the basis for benefits) 	
Congressional Testimony	Congressional Testimony -- Testimony before Congress by SSA officials	
Cost-of-Living Adjustment (COLA)	<ul style="list-style-type: none"> • 2008 COLA Information - Detailed Benefit, Tax and Wage-Indexed Changes for 2008 • 2008 COLA Fact Sheet • National average wage index and historical series • OASDI contribution and benefit base • Exempt amounts under the retirement earnings test • Amount of earnings a person must have to be credited with a quarter of coverage • "Old-law" contribution and benefit base • Domestic worker coverage threshold • Substantial gainful activity amounts for disabled beneficiaries 	
Death	Report a Death	
	Search SSA's Death Master File	
Direct Deposit of Benefits	A complete guide to the direct deposit of your monthly benefits.	Frequently Asked Questions About Direct Deposit
Disability Information	<ul style="list-style-type: none"> • Disability Planner • Social Security Disability Programs • Employment Support for People With Disabilities • Apply for Disability Benefits Online • Improving the Disability Determination Process - SSA Announces Proposed Regulation to Improve Social Security's Disability Process 	
Electronic Wage Filing	<ul style="list-style-type: none"> • Electronic W-2 Filing for Employers • FAQs on Wage Reporting 	
Employer Information	<ul style="list-style-type: none"> • Employer Reporting Instructions and Information • Names and Social Security Numbers -- A guide to assist employers in preparing accurate W-2s. • Verification of Names and Social Security Numbers • Frequently Asked Questions for Employers 	Frequently Asked Questions for Employers
	SSA Employment Opportunities	

Employment at SSA

The kinds of positions that SSA usually recruits for, the current job openings, employment office addresses and phone numbers, and how to apply for positions; resources are also included for:

- veterans
- people with disabilities
- students and college graduates
- bilingual-bicultural applicants

Equal Opportunity Data

[Equal Employment Opportunity Data Posted Pursuant to the No Fear Act](#)

Español

[Social Security Publications in Spanish](#)

Fax Catalog

[FAX Catalog -- Publications by FAX](#)

Feedback

[General Feedback on Social Security Online](#)
After searching a Frequently Asked Question database, you ask your question or leave your comment.

Financing Social Security

[The Trustees Report](#)--Financial Outlook for Social Security

Forms

[Social Security Forms](#) - Common forms that you need to do business with SSA. This page lists the forms or you can search the forms database.

Find your form using the Form Search Tool:

If you need a form that is not currently available for download, you should call 1-800-772-1213 (TTY 1-800-325-0778) to request the form.

Search:

All Fields

For:

Fraud

- [Office of Inspector General](#)
- [How to report fraud](#)

Freedom of Information (FOIA)

- [Freedom of Information reading room](#)
- [Our Web privacy policy](#)
- [Guide to Freedom of Information Act Requests](#)

Frequently Asked Questions

- [A searchable database of all of SSA's Frequently Asked Questions](#)
- [Frequently Asked Questions in Spanish](#)
- [Frequently Asked Questions for Employers](#)

Glossary

[Glossary of Social Security Terms](#)

[The Social Security Handbook](#) -- A

Handbook	comprehensive guide to all of Social Security's benefit programs	
Hearings and Appeals	Office of Disability Adjudication and Review (ODAR)	
History of SSA	History — A multimedia history of Social Security	
Identity Theft	Identity Theft And Your Social Security Number	Frequently Asked Questions on Protecting Your SSN
Immigration	A special page for recent immigrants to America.	
Inspector General	<ul style="list-style-type: none"> • Office of Inspector General • How to Report Fraud 	
International Programs and Benefits	Office of International Programs	
Kid's Pages	<ul style="list-style-type: none"> • Kids's Pages • What Every Parent Should Know About Social Security 	
Law and Legislation	<ul style="list-style-type: none"> • Compilation of Social Security Laws -- The full text of the Social Security Act, as Amended, and selected provisions of the Internal Revenue Code • Legislation -- Recent legislation affecting Social Security benefits • Congressional Testimony -- Testimony before Congress by SSA officials • History of the Social Security Act 	
Local Offices	<ul style="list-style-type: none"> • Use our Social Security Office Locator -- Type in your postal ZIP code and we will tell you how to contact your servicing office. • Visit one of our Regional Home Pages -- All ten regions have pages highlighting regional initiatives, local public information resources, and connections to local offices. 	
Medicare	<ul style="list-style-type: none"> • Medicare - The Official U.S. Government Site for Medicare Information • Centers for Medicare & Medicaid Services (CMS) - The Medicare and Medicaid Agency • Medicare Premium Information - The new rates for 2007 • Who to Contact - Information by State on who to contact about: <ul style="list-style-type: none"> ○ Your Medicare Bill 	Frequently Asked Questions on Medicare

- Getting Medicare, Other Health Insurance, Other Benefits
- Complaints, Appeals, and Other Medicare Rights
- Your Health Plan Choices
- [Information on the Medicare Prescription Drug Improvement and Modernization Act of 2003](#)
- [New Medicare Prescription Drug Plan](#)
- [Latest Information on TRICARE](#)

Multilanguage Page

[Social Security Information in 15 languages.](#)

Other Sites Of Interest

[Other Government Sites of Interest to Social Security Online Users](#)

Other SSA Sites -- [How We are Organized](#)

Password Services

Social Security offers password services. Choose from the options below:

- [Password Registration](#)
(Select this if you received a password request code from Social Security and would like to register your password.)
- [Change your password](#)
- [Block password access to your personal information](#)
(Select this if you have a password and no longer wish to use it, or if you received a letter from us about password services and you want to block access to your personal information .)
- [Lost or forgotten password or password request code](#) (Select this if you lost or forgot your password or password request code.)

Planning Documents

[Operational Finances](#) -- SSA's Performance and Accountability Report

Office of Policy

The Office of Policy serves as the Social Security Administration's focal point for policy analysis and research, evaluation, and statistics.

Learn more [about the Office of Policy.](#)

Step 2

Press Releases

[Social Security Administration Press Releases](#)

Prisoner Issues

[Questions and answers concerning payment of benefits to prisoners](#)

U.S. Social Security Administration, Office of Policy



The Office of Policy serves as the Social Security Administration's focal point for policy analysis and research, evaluation, and statistics. Learn more [about the Office of Policy](#) ← **Step 3**

Recently Released

Portfolio Theory, Life-Cycle Investing, and Retirement Income

Policy Brief No. 2007-02 (released October 2007)

There has been much discussion recently about life-cycle funds and their role in providing a secure retirement income for older Americans. These funds, which gradually shift account assets from broad-based stock funds to bond funds as a participant ages, are becoming an important vehicle for retirement savings. This policy brief explores the economic rationale behind the life-cycle approach and the advantages and limitations of life-cycle funds.

This document is available in the following formats: [HTML](#) [PDF](#)

Considerations for Potential Proposals to Change the Earliest Eligibility Age for Retirement

Policy Brief No. 2007-01 (released October 2007)

The earliest eligibility age (EEA) interacts with many other Social Security program rules, including the benefit formula and insured status requirements. Proposals to increase the EEA could affect some or all of these other rules depending on how policymakers design the proposal. By using a hypothetical proposal that increases the EEA, this policy brief illustrates how these interactions work and discusses the options that policymakers would need to consider.

This document is available in the following formats: [HTML](#) [PDF](#)

Quick Facts

- [Monthly Statistical Snapshot](#)
- [Program Highlights](#)
- [Frequently Asked Questions About Social Security's Future](#)
- [State Statistics](#)
- [Congressional Statistics](#)

Annual Statistical Supplement

The *Supplement* is a major resource for data on the nation's social insurance and welfare programs. The majority of the statistical tables present information about programs administered by the Social Security Administration—the Old-Age and Survivors Insurance and Disability Insurance programs, known collectively as Social Security, and the Supplemental Security Income program. In addition, data are presented on the major health care programs—Medicare and Medicaid—and income-maintenance programs. The *Supplement* also includes program summaries and legislative histories that help users of the data understand these programs.

Subsections of the *Supplement* will be posted on a flow basis as they become available.

- Edition currently in progress: [Annual Statistical Supplement, 2007](#)
- Most recently completed edition: [Annual Statistical Supplement, 2006](#)

U.S. Social Security Administration, Office of Policy About Us

Learn more about:

- [Major Responsibilities and Projects](#)
- [Organization and Staffing](#)
- [Partnerships](#)
- [Copyright and Use Policies](#)

← Step 4

U.S. Social Security Administration, Office of Policy Major Responsibilities and Projects

The Deputy Commissioner for Policy is the principal advisor to the Commissioner and Deputy Commissioner of Social Security on issues relating to Social Security solvency and retirement and income maintenance policy. The Deputy Commissioner for Policy heads the Social Security Administration's (SSA's) Office of Policy, which is responsible for the agency's policy analysis, policy research and evaluation, and statistical program. The Office of Policy plays a key role in supporting SSA's strategic goal of achieving sustainable solvency for Social Security and ensuring that the Social Security and Supplemental Security Income (SSI) programs meet the needs of current and future generations. It helps to educate the public about the financial challenges facing Social Security and provides decision makers with analyses of the economic, distributional, and administrative aspects of proposals to reform and modernize the program. Much of the office's work is made publicly available through a quarterly journal and numerous statistical publications, both in print and on the Internet.

Policy Analysis, Research, and Evaluation

The Office of Policy is responsible for analysis and research on policy initiatives for the Social Security Old-Age, Survivors, and Disability Insurance (OASDI) programs and the Supplemental Security Income program. Staff study the effects of those programs and of changes to them on individuals, the economy, and program solvency.

The Office of Policy places a high priority on analysis that provides policymakers with the information they need to understand the broad impact and distributional effects of reform proposals. For such analysis, the office develops and uses microsimulation models that estimate the consequences of proposed program changes on beneficiaries. For example, the MINT (Modeling Income in the Near Term) model is a microdata system that can be used to project demographic and economic characteristics of the baby-boom generation at retirement and into the future. The distributional analysis MINT provides makes a unique contribution to the solvency debate because it builds on actual earnings records matched with survey data.

Other important policy analysis and research activities include:

- In-depth analysis of Social Security reform proposals, including individual accounts;
- Analyses of the interrelationships between the Social Security system, the national economy, other income maintenance programs, and various socioeconomic factors;
- Research and analysis on the relationship of the disability programs to Social Security solvency and the financing of SSI;
- Analyses of options to simplify the SSI program;
- Studies of foreign and domestic retirement and income maintenance programs;
- Preparation of analytical material on OASDI and SSI beneficiary and payment provisions, employment, earnings, and employer classification; and
- Analyses of administrative issues, including the functions that would be required to administer individual accounts and their related costs.

Statistics and Data Dissemination

The Office of Policy is the agency's source for statistics on the impact and operations of the OASDI and SSI programs and on the earnings of the working and beneficiary populations. This function involves developing and maintaining a series of detailed statistical databases, preparing a broad range of statistical tables, producing statistical compilations and publications both in print and on the Internet, and developing information for special requests on current policy issues.

The statistical tables provide:

- Information useful in evaluating current programs and proposed legislative and program changes and in running the programs;
- Data on beneficiaries in individual states, localities, or congressional districts;
- Information about beneficiaries and expenditures of the Social Security program and other major social insurance and welfare programs;
- Specialized tables related to current issues; and
- Input to outside publications such as the Ways and Means Committee's Green Book and the Census Bureau's Statistical Abstract of the United States.

Users of these statistics include other SSA components, Congressional staff, other executive branch agencies, policy organizations, State and local governments, educational institutions, business organizations, and advocacy groups.

The microdata that SSA maintains on applicants for Social Security numbers, covered workers, and beneficiaries also provide an invaluable resource for research, statistical, and policy purposes. Demand for these data has been increasing, especially when they are linked to survey data such as the Census Bureau's Survey of Income and Program Participation and the University of Michigan's Health and Retirement Study. Those data are particularly relevant to the debate about the future direction of Social Security. Various laws and regulations control those data, access to them, and how they may be used. Public Law 103-296 authorizes the disclosure of vital status information for epidemiological research. Staff review each request to determine whether access is permitted and to ensure that users will protect the confidentiality of the data. Since the Internal Revenue Service (IRS) controls earnings data, requests involving such data must go through IRS's approval process. Social Security and the Bureau of the Census are also working to develop versions of those databases for public use.

Data Service for Epidemiological Research

SSA also provides a data service to health researchers involved in epidemiological research. Specifically, for studies that contribute to a national health interest, SSA will inform researchers about whether a subject of the study is alive or deceased. There is a fee for this service. For more information, see "[Service to Epidemiological Researchers to Provide Vital Status Data on Subjects of Health Research.](#)"



Step 5

U.S. Social Security Administration, Office of Policy

Service to Epidemiological Researchers to Provide Vital Status Data on Subjects of Health Research

OMB No. 0960-0701

Summary

Section 311 of the Social Security Independence and Program Improvements Act of 1994 directed the Social Security Administration (SSA) to provide support to health researchers involved in epidemiological research. Specifically, when a study is determined to contribute to a national health interest, SSA will furnish information regarding whether a study subject is shown on the SSA administrative records as being alive or deceased (vital status). SSA will recoup all expenses incurred in providing this information.

Contacts

This service is available as of this date by contacting the Office of Research, Evaluation, and Statistics (ORES):

Social Security Administration
Office of Research, Evaluation, and Statistics
4-C-15 Operations Building
6401 Security Boulevard
Baltimore, MD 21235-6401
Fax: 410-966-4071

In addition, further information about this service is available from the ORES Epidemiological Coordinator at the above contact points, by e-mail at ORES.Epidemiological.Requests@ssa.gov, or by telephone at 410-966-4868.

If you mail your request for this service via overnight express mail, please change the building location in the above address to:

Room 4700 Meadows East Building

Supplementary Information

Background

Historically, SSA had made disclosures of vital status data under the provisions of the Freedom of Information Act (FOIA, 5 U.S.C. 552(a)(3)). However, as a result of the Supreme Court decision in *United States Department of Justice v. Reporters Committee for Freedom of the Press* 489 U.S. 749 (1989), SSA discontinued the process of providing

such data. The enactment of section 311 of the Social Security Independence and Program Improvements Act of 1994 restored the legal authority for SSA to release vital status data except for death data obtained from a state under the auspices of section 205 (r) of the Social Security Act. A companion change to the Internal Revenue Code (26 U.S.C. § 6103) permits SSA to release "presumption of living" data based on reports of earnings obtained from the IRS. Accordingly, when the research in question has been determined to contribute to a national health interest, SSA will furnish vital status data on study subjects. The researcher must submit the study subject's Social Security number, full name (first, last, and middle name), date of birth (month, day, century, and year), and sex. SSA, in turn, will furnish one of the following vital status determinations for each study subject:

- Death information (the date of death and state where a claim was filed, or the state of residence at the time of death) if available;
- Presumption that the individual is living (there is sufficient information in SSA administrative records to support this determination);
- Status unknown (SSA has no record of death, nor sufficient information within the SSA administrative records to support a determination that the subject is alive);
- Social Security number (SSN) verification failed (the SSN and name furnished to SSA did not match or the date of birth furnished for an SSN/name did not match the information in the SSA administrative records); or
- The SSN was impossible or had never been issued.

Privacy Act Statement for Epidemiological Research Requests

The information requested by this application is authorized by the Privacy Act of 1974 (5 U.S.C. 552a), section 1106 of the Social Security Act (42 U.S.C. 1306), and regulations under title 20 C.F.R. 401.165. SSA will use the information you provide to document your request for vital status data, to evaluate whether you meet the criteria required for receipt of the data, and to bill you for the required payments. Information requested in this format is voluntary. However, if you do not provide the required information, we will be unable to process your request. While the information you furnish in this format would almost never be used for any purpose other than processing your request for epidemiological vital status data, such information may be disclosed by SSA to facilitate statistical research and audit activities necessary to ensure the integrity and improvement of programs administered by SSA.

Paperwork Reduction Act (PRA) Statement and OMB Control Number

This information collection meets the requirements of 44 U.S.C. 3507, as amended by section 2 of the Paperwork Reduction Act of 1995. You do not need to answer these questions unless we display a valid Office of Management and Budget control number. We estimate that it will take about 120 minutes to read the instructions, gather the facts, and answer the questions. You may send comments on our time estimate above to:

SSA
Room 1338 Annex Building
Baltimore, MD 21235-0001

Application Process

For each request for services, you must cover the following specific areas in separately numbered paragraphs:

1. Project or study title.
2. Applicant name, full address, phone number, fax number, and e-mail address.
3. Contact individual name (if different than applicant), full address, phone number, fax number, and e-mail address.
4. Project coordinator name, full address, phone number, fax number, and e-mail address.
5.
 - a. Name of sponsoring organization or institution supporting the research.
 - b. Name (and title, if available) of specific person who will sign the agreement and reimburse SSA for expenses incurred in supplying data.
 - c. Employer identification number (Social Security number if not a business).
6. Data custodian's name, full address, phone number, fax number, and e-mail address.
7. Attach a one-page summary of the study protocol of the project activities. Include specific purposes(s) of the research to be undertaken and the outcomes expected.
8. Estimated number of records you will submit. To protect data from theft or modification, SSA recommends that requestors encrypt all input files prior to submission. Submitting unencrypted data to SSA is not recommended and is done at the requestor's own risk.
9. Fully explain how the data provided by SSA will be used. Specify whether the data will be used only to determine the subjects' vital status or whether it will also be used to obtain death certificates to determine the causes of death or to obtain additional information from next-of-kin, physicians, or hospitals.
10. Provide the final disposition of SSA data to include the location of files and full disclosure of who will have access to the identifying data on the "presumed living" and for how long. In addition to the staff of the requesting organization, list any "other party" that will receive (or have contractual or other rights to) any identifying vital status information provided by SSA on the "presumed living." Note that all organizations that will receive identifying information on the "presumed living" must become a party to the agreement. All individuals accessing such data must sign a confidentiality agreement.
11. If applicable, fully explain how the applicant plans to publish or release the research results, including whether any supporting documentation will be made available in identifiable form on the "presumed living."
12. Provide a [data protection plan](#) describing how you will ensure the confidentiality of the vital status data supplied by SSA on the "presumed living."
13. Include a statement that the above applicant fully understands that the vital status data obtained from SSA on the "presumed living" will only be used for the purposes described in this request and will not be used for administrative or legal purposes.
14. Include a statement that the applicant hereby agrees to ensure the confidentiality of the vital statistics supplied by SSA on the "presumed living" as described in the data protection plan (item 12).
15. Applicant's signature.

NOTE: If the applicant indicates that other organizations or individuals will receive identifying SSA vital status data on the "presumed living," that organization must also be a party (signatory) to the applicant's memorandum or must submit a separate supporting memorandum. In this supporting documentation, each third party must indicate (1) their role in the study and the activities they will perform, (2) a [data protection plan](#) describing how they will store the identifying data on the "presumed living" and maintain the confidentiality of such data, and (3) how and when the identifying data on the "presumed living" will be destroyed.

An evaluation team comprising staff members from SSA's Office of Research, Evaluation, and Statistics and the National Center for Health Statistics (NCHS) will review each application for services. The team will not attempt to determine the scientific merit of the study. It is understood that the merit of the study has been (or will be) determined by the sponsoring agency and/or the organization performing the study. The team's purpose will be to reach a consensus that the results of the study could be expected to advance the public's knowledge in a health area of importance to a segment of the United States population.

If such a determination is made and the Associate Commissioner for Research, Evaluation, and Statistics concurs, the applicant will be notified, in writing, of the methods that may be used to submit data on study subjects, the exact format to be used in submitting this data, and the cost for developing and transmitting the vital status data from SSA records. The applicant will be required to sign a memorandum of understanding that will delineate his or her responsibilities in the use of the requested vital status data. The applicant will also be required to sign a contractual agreement to facilitate payment for the service.

The Social Security Administration will recoup all costs (computer program development costs and ongoing processing costs) associated with this service. The service is currently available (for fiscal year 2008) at a cost of \$0.21175 per record (data supplied to identify one study subject) up to 25,000 records. Additional records will be processed at a cost of \$0.03905 per record. These rates are subject to change to reflect actual costs in subsequent years. Form SSA-1234-U5 "Agreement Covering Reimbursable Services" will be signed by the applicant and an appropriate SSA representative to formalize the payment process. Nonfederal requesters are required to provide an advance payment of 100 percent of the SSA costs for this service.

Criteria Used to Approve Requests

The SSA/NCHS team will use the following criteria in formulating their recommendations for the Associate Commissioner for Research, Evaluation, and Statistics:

- **Use of Data for Statistical Purposes.** The request for services should clearly state that the vital status data supplied will be used to support statistical calculations and/or study findings. Furthermore, the request must indicate those situations in which the death data furnished will be used to identify state death records. A request will be disapproved if it proposes to use the vital status data or state death data obtained from the vital status data for administrative, law enforcement, or other nonstatistical purposes. The team can suggest that the applicant be given the

opportunity to revise the application to eliminate any nonstatistical uses of the vital status data.

- **Disease Registries.** Requests from individuals and or groups working with disease registries will be accepted. By "disease registry" is meant a roster of persons diagnosed and/or treated for a particular disease and maintained for the purpose of morbidity and/or mortality surveillance without any specific hypotheses to be examined. Registries usually employ a standardized methodology, are subject to informal and sometimes formal controls, and may rely on other methods for follow-up of a majority of the roster. Such registries deserve special considerations. Applicants who propose to submit a roster of names deriving from such a registry should specify the date the registry was founded, the purposes of the registry, the eligibility criteria for including persons in the registry, the provisions for internal and external approval of the registry's quality and methods (including human subject considerations), and the dates of the last documented internal and/or external reviews.

SSA will generally approve these submissions provided the requests give adequate documentation of the registries' activities.

Furthermore, registries will not be required to submit separate applications for each study. Multiple uses of SSA vital status data are permitted provided that (1) each study is solely for statistical purposes in medical and health research, (2) adequate assurances are given that the confidentiality of the identifying vital status data on the "presumed living" will be maintained, and (3) vital status data on the "presumed living" will be kept separate from any administrative records.

- **Mortality Follow-up on Non-Disease Cohorts.** Most applicants are required to submit separate requests for specific studies. However, some organizations conduct mortality surveillance studies on "non-disease" cohorts such as industrial workers, population samples, and members of particular families, and the vital status data on those individuals may be used for multiple epidemiological studies. Such organizations, in essence, are maintaining exposure or other non-disease "registries" that facilitate epidemiological studies of groups with particular experiences. Such organizations will not be required to submit separate applications to SSA for each study, although they will be required to describe expected protocols and give specific, current, or future examples.

Multiple uses of vital status data obtained from SSA on the "presumed living" are permitted provided that (1) each study is solely for statistical purposes in medical or health research, (2) adequate assurances are given that the confidentiality of the identifying vital status data on the "presumed living" will be maintained, and (3) vital status data on the "presumed living" will be kept separate from any administrative records.

- **Use of Data by a Third Party.** If the applicant indicates that another organization will receive identifying SSA vital status data on the "presumed living," that organization must be a party to the original submittal or submit a supporting memorandum. In this supporting documentation the third party must indicate (1) their role in the study and the activities they will perform, (2) a [data protection plan](#) describing how they will store data and maintain the confidentiality of data on the

"presumed living," and (3) how and when data on the "presumed living" will be destroyed.

- **Final Disposition of Data.** The applicant must indicate if, how, and when identifiable data on the "presumed living" furnished in support of a request will be destroyed. If there is no indication that the identifiable data on the "presumed living" will be destroyed, the individual requesting the vital status data must explain, in some detail, why the data need to be maintained.

Repeated Use of the Service

Once an applicant is approved to obtain vital status data for a specific study or project, the approval is valid for 2 years as long as there are no major changes in the project. Additional records may be submitted under the approved contract for services. If, however, the project specifications change, the applicant must submit a new request for services. The following is a list of possible occurrences that would require the submission of a new request for services:

- The project will be supported by a new organization;
- A new organization will be receiving vital status data;
- Confidentiality provisions on the "presumed living" have changed;
- Provisions for disposing of data on the "presumed living" obtained from this request have changed;
- Vital status data on the "presumed living" will be used for legal, administrative, or other actions that could directly affect particular living individuals or establishments;
or
- Changes have been made in the project's research objectives.

Guidance for Preparing a Data Protection Plan

As a potential user of SSA sensitive data, you must submit an SSA Data Protection Plan for approval. You must specify in your SSA Data Protection Plan how you will keep SSA data on the "presumed living" secure and confidential on a variety of media, including magnetic tapes, hard disks, and other fixed magneto-optical media; compact disks, diskettes, and other removable magneto-optical media; and paper. Use the following Guidance for Preparing an SSA Data Protection Plan to write your SSA Data Protection Plan. Describe in detail each provision listed.

The safeguards shall provide a level and scope of security that is not less than the level and scope of security established by the Office of Management and Budget (OMB) in OMB Circular No. A-130, Appendix III - Security of Federal Automated Information Systems (<http://www.whitehouse.gov/omb/circulars/a130/a130.html>) which sets forth guidelines for security plans for automated information systems in federal agencies.

SSA sensitive data includes any data in identifiable form from SSA's administrative records about the "presumed living."

Your SSA Data Protection Plan must cover the following areas:

1. Security/Physical Safeguards of the Computing Environment

We strongly recommend that you use a self-contained Local Area Network (LAN) or a stand-alone computer(s) because of the potential security problems that can occur in timesharing mainframes or LANs. If you do use a timesharing platform, be very specific in describing the security and safeguards that you will use to protect our data.

Provide a detailed description of the security/physical safeguards of the computing environment in which you will be managing and analyzing the data. For each item of the computing equipment you will be using (CPU, tape drives, printers, and so on), describe:

- a. Where they are located;
- b. Who has physical access to them;
- c. The security provisions that restrict access to only authorized users of the data on the system(s) you will be using, such as locked doors, locks on equipment, passwords, encryption, and so on;
- d. The routine procedures for making backup copies of data files on tape or disk;
- e. The system as a whole as well as your terminal;
- f. The access system administrators have to files and passwords [for shared file systems only]; and
- g. The audit trails that you maintain to identify users, authenticate users, and trace users' actions on your system. This enables you to maintain individual accountability of all data users.

2. Restricted Access—Fixed Storage Media

Provide a detailed description of how you will restrict access (for example, password protection) to hard disk or other electromagnetic, optical, or similar fixed storage device files containing the data. Indicate the kind of storage data you will be using and describe:

- a. Where the storage devices to be used are physically located;
- b. How you will restrict physical access to only authorized persons;
- c. How you will restrict access to the contents of hard disk and similar storage device files to only authorized persons, such as through a system of encryption and/or passwords;
- d. How you will restrict access to files to which only authorized users have "read" and "write" permission;
- e. How you will prevent routine system backups of hard disk and similar storage device files, regardless of type of backup medium;
- f. How you will prevent access to files by system administrators [for shared file systems only];
- g. Clearly state in your plan that no more than one backup copy will be made of any hard disk or similar storage device file containing the data; and
- h. When (on or before the date on which your authorized access to the data expires) and how all such copies will be destroyed.

3. Restricted Access—Removable Storage Media

Provide a detailed description of how you will restrict access to compact disks, diskettes, and other removable electromagnetic or optical storage media files. We strongly recommend against the use of removable media for data storage, except as a means of shipping data to and from SSA. If used, describe:

- a. How you will use removable media data storage;
- b. Where the removable media to be used will be physically located;
- c. How physical access to them is to be restricted to only authorized persons, including provisions for storage in locked cabinets when not in use;
- d. Which mechanisms will be used to ensure that only authorized persons will be able to mount and read removable media; and
- e. Which mechanisms (for example, computing systems that require the use of keywords or labels known only to the owner of the removable medium, to mount the medium) will be used to ensure that only authorized persons will be able to mount and read removable media handled by a central system [for shared file systems only].

4. Printed Output

Provide a detailed description of how you will restrict access to paper printouts containing SSA data. SSA strongly recommends against the creation of any paper printouts of its data. If used, describe:

- a. The uses that will be made of such printouts;
- b. The reasons why no other media can be used for the same purpose;
- c. The means by which you will ensure that such printouts are handled by authorized persons only;
- d. How they will be kept in locked storage, accessible only to authorized persons when not in use;
- e. How they will be kept from the vision and reach of unauthorized persons when they are in use; and
- f. How they will be destroyed (for example, made unreadable through burning or shredding) after completing any analysis.

5. Derivations of SSA Data

Provide a clear and detailed statement that you will treat all derived SSA data in the same manner as the original SSA data, and that you understand that derived SSA data includes but is not limited to:

- Subsets of cases or variables from the original data;
- Numerical or other transformations of one or more variables from the original data, including sums, means, logarithms, or products of formulas; or
- Variables linked to another data set using variables from the original data as linkage variables.

NOTE: Aggregated statistical summaries and analyses of the original data, such as tables and regression formulas, are not "derived variables" and, unless otherwise specified in the Memorandum of Agreement (MOA), are not subject to the requirements of your plan.

6. Linkages to Other Data

Provide a clear and detailed statement that you will not link any other data to the original data specified in the MOA. Your statement must also include recognition that you will not link the original data or derived data set(s) to any other SSA data set(s) without our explicit written permission.

7. Training for Individuals Who Will Have Access to Confidential Data

All individuals who will have access to SSA data in identifiable form must understand the security and safeguard provisions required to ensure the confidentiality of SSA data. Explain how you will train these individuals so they are familiar with the safeguarding provisions in your SSA Data Protection Plan. In addition, they will be required to sign a [Confidentiality Agreement](#).

Explanatory Notes

Authorized Persons

Authorized persons include the Custodian(s), the Principal Investigator(s), and any other persons or data users designated in the Memorandum of Agreement.

SSA Sensitive Data

SSA sensitive data contain identifiable personal information and information meant to be kept confidential as covered under SSA Regulation No. 1, the Privacy Act of 1974, the Tax Reform Act of 1976, and Section 1106 of the Social Security Act of 1974.

Encrypted SSA Data

Where encryption is needed, encrypt SSA data using the Digital Encryption Standard, the only data encryption standard approved by the National Institute of Standards and Technology (NIST) for use by federal agencies at this time.

Faxing SSA Data

We prefer that you not fax SSA data. However, if you do fax SSA data, documents must be properly labeled, the fax telephone number must be verified, and an authorized person must be at the fax machine prior to sending the document.

E-mailing SSA Data

We prefer that you not e-mail SSA data. However, if you do e-mail SSA data, it must be encrypted as an attachment to the mail message and sent to an authorized person only.

Protected Communications

We prefer that you not electronically transmit SSA data. However, if you do electronically transmit SSA data over external networks, dedicated lines must be used or the data must be encrypted and an authorized person must be at the receiving end prior to the transmission.

Acceptable Delivery of SSA Data

You must deliver SSA data only to authorized personnel and by delivery services that provide tracing services such as certified mail, priority mail, or Federal Express. All packages must be properly sealed, labeled and reinforced, and enclosed with a list of the contents being sent.

Destruction of SSA Data

All SSA data not returned must be destroyed by the end of the project date as described in the MOA. SSA data can be destroyed by **burning or shredding**. If the data are burned, use EPA-approved public incinerators to burn it and examine ash residue and re-burn if any large pieces are not totally destroyed the first time. If the data are shredded, use shredders that reduce residue particle size to 3/16 of an inch or less in width.

Clearing Magnetic Media

Magnetic media (tapes, disks, hard drives) containing SSA data must be destroyed or erased prior to reuse. To erase, overwrite SSA data a minimum of three times with a commercial disk utility program. If you are unable to overwrite, degauss using a commercial degausser.

Proper Labeling

All stored or transferred SSA data, electronic or nonelectronic, must be labeled **"DISCLOSURE PROHIBITED—THIS CONTAINS SENSITIVE INFORMATION—SSA RESTRICTED DATA."**

Confidentiality Agreement

All individuals who will have access to SSA data on the "presumed living" in identifiable form must sign and date the [Confidentiality Agreement](#). ← **Step 6**

Confidentiality Agreement

Purpose: This form is for all users of SSA sensitive data to certify that they understand SSA's security, confidentiality and ethics requirements.

I understand the SSA security, confidentiality, and ethics requirements and agree that:

1. I will comply with all the confidentiality and legal requirements as stated in the contract, Memorandum of Agreement (MOA), or other documentation when using SSA sensitive data.
2. I will follow all security and safeguard provisions as described in the SSA Data Protection Plan when using SSA sensitive data.
3. I agree not to construct and maintain, for a period of time longer than stated in the contract, MOA, or other documentation, any file containing SSA sensitive data unless explicitly agreed to by SSA in writing.
4. I agree not to link any other data to the SSA sensitive data described in the contract, MOA, or other documentation or any derived data set(s) unless explicitly agreed to by SSA in writing.
5. I will use proprietary software, that is, computer software that complies with federal copyright laws and licensing agreements.
6. I agree to keep confidential any third-party proprietary information that may be entrusted to me as part of the contract, MOA, or other documentation.
7. I will not release or disclose any information subject to the Privacy Act of 1974, section 6103 of the Internal Revenue Code, SSA Regulation 1 (20 C.F.R. Part 401), and section 1106 of the Social Security Act to any unauthorized person.
8. I understand that I may be subject to a site inspection(s) by SSA to ensure that adequate security safeguards, controls, and confidentiality are maintained as specified in the SSA data protection plan and in the contract, MOA, or other documentation.
9. I understand that disclosure of any information to parties not authorized by SSA may lead to civil or criminal prosecution under federal law and/or regulations.
10. I understand that I can be subject to a personnel security and suitability background investigation.

User signature

Date