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

Summary

Section 1106(d) of the Social Security Act directs the Social Security Administration (SSA) to provide support to researchers involved in epidemiological or similar research. Specifically, SSA will furnish information about whether study subjects are shown on SSA records to be alive or deceased pursuant to Section 1106(d), only when SSA in consultation with the Department of Health and Human Services finds that the research may reasonably be expected to contribute to a national health interest. The requestor must agree to reimburse SSA for expenses incurred providing the information and comply with all privacy safeguards.

Contact

This service is available through the Office of Data Exchange and Policy Publications (ODEPP) by completing a data exchange request form available on their website. If you have questions about the epidemiology service, e-mail ORDP.Data.Exchange@ssa.gov. Provide as much detailed information as possible including, contact information, description, and purpose of your data exchange request.

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 1106(d) of the Social Security Act restored the legal authority for SSA to release vital status data, except for death data obtained from a state under Section 205(r) of the Social Security Act. However, if you are a federal or state agency, you may be eligible to receive all death records, including death data received from the states. In addition, a companion change to the Internal Revenue Code (26 U.S.C. § 6103(l)(5)(B)) permits SSA to use tax return information to determine the mortality status of individuals for epidemiological research in accordance with Section 1106(d) of the Act.

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 program records to support this determination); or
- Status unknown (SSA has no record of death, nor sufficient information within the SSA program records to support a determination that the subject is alive);

No additional information is provided for records that could not be verified.

Application Process

Please complete a data exchange request form. Please complete numbers 1-7, 9-23, and 30-38. Please leave numbers 8 and 24-29 blank.

The data exchange request form contains instructions. However, here is additional guidance specific to your vital status request:

- Use number 4 to explain that you are seeking the potential vital status determinations (bulleted above) for each study subject.

- Use number 5 to indicate that you will submit each study subject's Social Security Number, full name (first, last, and middle name), date of birth (month, day, century, and year), and sex.

Space for responding to each question on the data exchange request form is limited. If you need additional space, you may continue typing on blank sheets of paper. Attach those additional sheets of paper to the data exchange request form.

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. 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 important to a segment of the United States population.

If SSA determines that it can approve the application, the applicant will be required to sign a memorandum of understanding that delineates 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 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 these data, and the cost for developing and transmitting vital status data from SSA records.

SSA will recoup all costs (computer program development costs and ongoing processing costs) associated with this service. The applicant and an appropriate SSA representative will sign Form SSA-1235 "Agreement Covering Reimbursable Services." Nonfederal requesters must provide an advance payment of 100 percent of SSA's costs for this service.

Criteria Used to Approve Requests

The SSA/NCHS team will use the following criteria in formulating their recommendations for approving vital status data requests:

- *Use of Data for Statistical Purposes*. The request for services should clearly state the epidemiology or similar research purpose for the requested vital status data.

- *Disease Registries*. Requests from individuals and or groups working with disease registries may be accepted. "Disease registry" means 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. Applicants who propose to submit a roster of names from such a registry should specify the date the registry was founded, the purposes of the registry, the eligibility criteria for inclusion, the registry's quality and method approval processes (including human subject considerations), and the dates of the last documented internal and/or external reviews.

  Furthermore, registries may not be required to submit separate applications for each study.

- *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 may not be required to submit separate applications to SSA for each study, although they must describe expected protocols and give specific, current, or future examples.

- *Final Disposition of Data*. The applicant must indicate agreement with SSA's standard requirement that the recipient return or securely destroy SSA provided data when it

has no further need for the information or upon termination of our agreement with the recipient, whichever occurs first.