

The Social Security Administration “Presumed Living” Search

We recently identified an important new tracing resource available from the Social Security Administration (SSA). For many years, Westat, Inc, has purchased copies of the annual SSA Death Master File¹ as a cost-effective method for conducting mortality follow-up of subjects under study by researchers at the National Cancer Institute. Thus, it has been some time since we last sought vital status information directly from the SSA. Historically, the SSA has provided only date of death and state of claim (or state of residence at the time of death) for decedents.

During a recent review of the SSA's Internet home page (<http://www.ssa.gov/search/index.htm>; search term= presumed living), we learned that, pursuant to the enactment of Section 311 of the Social Security Independence and Program Improvements Act of 1994, the SSA is now authorized to release to health researchers vital status data for living subjects as well as for decedents.² If the SSA determines that the research will contribute to a national health interest, researchers may submit records that include Social Security number, full name, date of birth, and sex. In return, the SSA will provide a vital status determination for each study subject in one of the following categories: deceased (with accompanying data, as just mentioned), presumed living, status unknown, failed Social Security number verification, or Social Security number invalid or never issued.

Successful linkage is determined by a match on Social Security number (exact), name, and date of birth. The SSA applies 12 rules for determining matches on names, allowing for variations in spelling, compound names, and transposed, missing, or extraneous letters. A 1-year window is applied to year of birth if month of birth matches exactly.

Vital status information is derived from administrative files maintained by the SSA, including death claims filed by beneficiaries, contributions made to the SSA through payroll deductions, and benefits currently received (i.e., retirement or disability payments). In addition, a companion change to the Internal Revenue Code³ authorized SSA to release “presumption of living” data based on earnings reported to the Internal Revenue Service. Vital status data are said to be current within the previous 2 years. The complete vital status search is available at a cost of \$0.16 per record for the first 25000 records, with additional records processed at \$0.012 per record.

We are currently conducting a multicenter study of 5573 female scoliosis patients diagnosed between 1912 and 1965 to evaluate risk

of breast and other cancers following diagnostic x-rays received during treatment and monitoring for spinal curvature.⁴ Follow-up of patients in this cohort was complicated by the fact that most were last seen as teenagers and information was not generally available on name changes resulting from later marriages. Telephone tracers engaged in one-on-one tracing of patients and their fathers, mothers, and husbands (upon identification). Tracing resources included records from the SSA, the Health Care Financing Administration, the National Death Index, town books (in Massachusetts), motor vehicle bureaus, credit companies, the US Postal Service, directory assistance, commercial telephone listings, and neighbor search databases. Social Security numbers were determined for 5264 (nearly 95%) patients.

To evaluate the usefulness of the new SSA vital status search, we searched in January 1999 all scoliosis patients who were not known to be deceased (n=4332). Identifying information included Social Security number (100% complete), first name (100%), middle name (73%), last name (100%), sex (100%), and birth month (99%), day (98%), and year (100%). The SSA reported that 154 (4%) patients were deceased, 2917 (67%) patients were presumed living, 861 (20%) patients were of unknown status owing to insufficient data, 282 (7%) subjects' names did not match their Social Security numbers, 113 (3%) subjects' dates of birth did not match their Social Security numbers, and 5 (0.1%) Social Security numbers were invalid or never issued.

Vital status through January 1, 1997, for the entire cohort, including those previously known to be deceased, is shown in Table 1. When the SSA returns were merged with existing follow-up data (allowing for a 2-year lag), we identified 16 new deaths and converted 647 women from “lost to follow-up” status to presumed living. Overall, the lost to follow-up group was reduced by more than half, from 23% to 11%. A similar pattern was seen for all birth cohorts, although the reduction in individuals lost to follow-up was progressively greater in more recent cohorts, ranging from 22% for patients born before 1920 to 74% for those born in 1950 or later. The lost to follow-up group was reduced by 24%, 54%, 67%, and 69%, respectively, among patients last known to be alive during the following calendar periods: pre-1940, 1940 through 1959, 1960 through 1979, and 1980 or later (data not shown).

We conclude that the recently available SSA service offers an effective and inexpensive method of determining vital status for epidemiologic research subjects lost to follow-up.

TABLE 1—Vital Status Through January 1, 1997, for Female Scoliosis Patients Before and After Linkage With US Social Security Administration Records, by Birth Cohort

Birth Cohort	No. of Patients	Before Linkage			After Linkage			Change in LTF, %
		Alive, No. (%)	Deceased, No. (%)	LTF, No. (%)	Alive, No. (%)	Deceased, No. (%)	LTF, No. (%)	
Pre-1920	541	118 (22)	223 (41)	200 (37)	154 (29)	232 (43)	155 (29)	-22
1920-1929	1184	486 (41)	366 (31)	332 (28)	612 (52)	375 (32)	197 (17)	-41
1930-1939	923	489 (53)	190 (21)	244 (26)	635 (69)	188 (20)	100 (11)	-59
1940-1949	1908	1407 (74)	179 (9)	322 (17)	1622 (85)	180 (9)	106 (6)	-67
1950 or later	1017	778 (77)	72 (7)	167 (16)	902 (89)	71 (7)	44 (4)	-74
Total	5573	3278 (59)	1030 (19)	1265 (23)	3925 (70)	1046 (19)	602 (11)	-52

Note. LTF = lost to follow-up.

This resource is most useful in determining vital status for subjects with more recent dates of birth and last known status; however, in our search, we found substantial proportions of older patients and those lost to follow-up many years in the past. The principal limitation of the resource is that addresses are not provided for subjects who are identified as presumed living. On the other hand, knowledge of vital status is of paramount importance in some studies (e.g., mortality analyses) and is tremendously useful for efficiently and effectively channeling tracing activities and resources to obtain location information. □

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Contributors

M. M. Doody planned the study, analyzed the data, and wrote this research letter. K. Chimes identified the newly available presumed living tracing resource, coordinated record linkage with the Social Security Administration, and contributed to the writing of the letter.

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