

Exemption:	Z-Draft of proposed legislation - archival records exemptions
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The section below in your Z-Draft may need to be revised based on information contained in the article, also below: (2) Access to social security numbers for the purpose of inspection and copying is in accordance with federal and state laws. Under 42 U.S.C. Sec. 405, social security numbers are available to the public after a person's death. The United States social security administration maintains a master death file that is used to verify death and prevent fraud. The master death file is available to the public and it discloses the person's name, dates of birth and death, social security number, last place of residence, and the location where the social security number was issued.

[http://www.nytimes.com/2012/10/09/us/social-security-death-record-limits-hinder-researchers.html?google\\_editors\\_picks=true](http://www.nytimes.com/2012/10/09/us/social-security-death-record-limits-hinder-researchers.html?google_editors_picks=true) A shift last year by the Social Security Administration to limit access to its death records amid concerns about identity theft is beginning to hamper a range of research, including federal assessments of hospital safety and efforts by the financial industry to spot consumer fraud. For example, a research group that produces reports on organ transplant survival rates is facing delays because of the extra work it must do to determine whether patients are still alive. The federal agency that runs Medicare uses the data to determine whether some transplant programs have such poor track records that they should be cut off from government financing. “We are not going to be on time until this problem is corrected,” said Dr. Bertram L. Kasiske, a Minneapolis nephrologist who directs the research group, the Scientific Registry of Transplant Recipients. “It’s a big deal. A lot of people look for these reports and depend on them.” Other medical researchers, including those conducting long-term federally financed studies of cancer and cardiovascular treatments, said the changes imposed last November were now slowing their work significantly. And a spokesman for financial industries like life insurance, banking and credit services said the change was making it more difficult to detect identity thieves who steal names and Social Security numbers from the deceased. “There is already a consequence — there has to be — because there are fewer records available,” said Stuart Pratt, the president of the Consumer Data Industry Association. The Social Security Death Master File is an index of 90 million deaths that have been reported to the agency over 75 years by survivors, hospitals, funeral homes and state offices. The listings include names, Social Security numbers and dates of death. The agency did not make the information public until 1980, after a legal ruling required that the data be disclosed. The list is updated weekly, and although it is neither comprehensive nor 100 percent accurate, it is considered the most current record of deaths nationwide, making it a rich trove for researchers. It is also far more affordable for researchers than the leading alternative, a death index kept by the federal Centers for Disease Control and Prevention that, while more complete, is typically 14 months to 18 months out of date. For a decade, the Social Security master file routinely included records provided by the states. But last year, after reports that

the widespread availability of death records was facilitating identity theft, the Social Security Administration determined that it had been improperly releasing the state records as part of the file. Under a 1983 law, the agency concluded, those state records — but only those records — were exempted from public disclosure. They could, however, be made available to other federal agencies, like the Internal Revenue Service and the Centers for Medicare and Medicaid Services, that needed them to determine whether to pay or discontinue benefits. As a result, four million deaths were expunged from the publicly available master file last November. Social Security officials expect the number of deaths disclosed each year — 2.8 million were made public in 2010 — to decrease by one million. For epidemiologists, it can be critical to learn quickly when the subject of a study has died so that details can be gathered while memories and records are fresh. Without an updated national index, it can be difficult to track those who have moved repeatedly or perhaps died alone. Jesse D. Schold, a health researcher at the Cleveland Clinic, said the holes in the master file, which will only grow larger, had already compromised his investigation into mortality rates among living kidney donors. Confirming deaths of subjects by surveying every state would be prohibitively burdensome, he said. And using the index compiled by the C.D.C., which pays states to submit refined data, would be unaffordable, costing perhaps \$30,000 to \$50,000 a year. By contrast, an annual subscription to the Social Security file, with unlimited searches, can be bought for as little as \$995. Genealogy Web sites make the data available on the Internet at little or no cost. “It’s very critical that we have an objective way to measure deaths,” Dr. Schold said. “Otherwise we’re getting the data from the centers we’re measuring, and that’s problematic” because they cannot track all former patients until death. Gary Chase, the senior project manager of the Nurses’ Health Study, a 36-year Harvard examination of cancer prevalence among more than 200,000 women, said the new policy had “thrown us back to the pre-Internet era, where you’d start looking in the phone book for someone with a similar name and sending out a bunch of letters.” Greta Lee Splansky, the director of operations for the Framingham Heart Study, which is based at Boston University, said the withheld records meant “the loss of a very valuable tool.” Over six decades, the study has examined the causes and effects of heart disease in three generations of subjects who were originally from the same town in Massachusetts. Many are dying off. “It just slows us down,” Ms. Splansky said. “It’s wasting research dollars.” Mark Hinkle, a spokesman for the Social Security Administration, said researchers would simply have to collect the data from the states. “I don’t want to sound offensive,” Mr. Hinkle said, “but our job is to administer the Social Security program, and administering a death list really isn’t in our core set of workloads. The bottom line is that we have to follow the laws and administer the programs we’re supposed to administer.” In response to pressure from panicked medical researchers, the C.D.C. hopes to start updating its death index more quickly, but it will not be able to reduce the cost, said Charles J. Rothwell, the director of vital statistics. Federal agencies with a stake in medical research have been lobbying Social Security officials to consider a compromise. In Congress, concerns about identity theft — some driven by tax fraud cases involving deceased children — have prompted proposals to restrict access even further. Representative Sam Johnson, Republican of Texas, has introduced legislation to end the public disclosure of the master file altogether. Senator Bill Nelson, Democrat of Florida, has proposed a bill that would keep death records private until three years after a person died. Mr. Johnson seems unmoved by the researchers’ plight or by the argument that his bill would hobble the detection of consumer fraud even as it seeks to

disarm the thieves. “The decades-old practice of publishing personal death information that anyone can buy needs to end,” he said, “and now.”