Dead or alive: The elusive quest for long-term follow-up

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Accurate ascertainment of vital status is a critical component of medical research and quality improvement programs, and one of the most difficult to achieve. Researchers in the United States have relied on a combination of tools in addition to the traditional local techniques of searching the medical record, calling patients, and screening obituaries. The 2 most important tools used in the past were the Social Security Death Master File (SSDMF),¹ also known as Social Security Death Index, and the National Death Index (NDI) from the Centers for Disease Control and Prevention.²

The SSDMF is a database collected from death reports received by the Social Security Administration (SSA) from many sources to administer its programs. In 1980, after a legal ruling, the SSA started providing public access to the entire master file.³ In November 2011, however, after concerns arose about identity theft of recently deceased individuals and the argument was made that the SSA is not justified to disclose information provided by individual states, all death records received from states were removed. This amounted to removing 4.2 of the 89 million records that the file contained in 2011 and translated into adding 1 million fewer records annually.⁴ The SSA now keeps 2 separate files: the "full file," which is shared only with federal and state agencies, and the "public file," which excludes death data received from states. As such, the SSDMF is no longer a reliable source of follow-up information.^{5,6}

The NDI is a resource that collects data directly from the states and provides information to clinical investigators.² Even though the NDI has always been a more reliable source of data than the SSDMF (sensitivity 87%-98% for NDI vs 83%-84% for SSDMF)⁷⁻⁹ and contains information on cause of death, it requires an application that takes 2 to 3 months to be approved, is available 15 to 16 months after the end of the respective calendar year, and is relatively expensive, especially for large data sets (eg, 1000 records searched against 10 years would cost \$1850).²

The advantages of being able to link large data sets such as the Society of Thoracic Surgeons (STS) Database to vital status registries for quality assurance purposes would be

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Central Message

The Social Security Death Index is no longer a reliable source of long-term follow-up data. Tools available to researchers are now limited to conventional methods or the National Death Index.

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tremendous. In 2011, Jacobs and associates¹⁰ proved that linking the STS Database to the SSDMF was feasible, opening the door to the possibility of providing each participating program with long-term survival data as part of their regular report. The STS is to be commended for their continuous efforts in exploring different options, as explained by Jacobs and colleagues⁶ in this issue of the *Journal*.

So, what options do medical researchers currently have to obtain follow-up data? Unless they are able and willing to invest the time and resources needed to obtain data from the NDI, local traditional methods may be the only way. It is ironic that in 2017, in the middle of the digital and social media age, we remain stuck hoping that, one by one, each of a study's subjects will pick up the phone when we call them, and let us know whether they are dead or alive.

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