



April 16, 2015

The Honorable Ron Johnson
Chairman
Senate Homeland Security & Governmental Affairs Committee
U.S. Senate
340 Dirksen Senate Office Building
Washington, DC, 20510

The Honorable Thomas Carper
Ranking Member
Senate Homeland Security & Governmental Affairs Committee
U.S. Senate
340 Dirksen Senate Office Building
Washington, DC, 20510

RE: Access to the Death Master File

Dear Chairman Johnson and Ranking Member Carper:

The undersigned members of the Physician Clinical Registry Coalition look forward to working with you on the Stopping Improper Payments to Deceased People Act to ensure death data maintained by the federal government can once again be used to further clinical research and health care quality improvement efforts of vital importance to our changing health care system.

Prior to November, 2011, entities like clinical data registries could purchase death information compiled from the complete Social Security Death Master File (DMF). These data, when matched with the registries' clinical information, were used to generate quality improvement strategies based on longitudinal observations of patient outcomes. Our experiences have shown that research based on this information improves surgical outcomes, helps with patient decision-making on treatment options, and enhances the quality of patient care. In fact, the National Institutes of Health funded a number of studies based on this research model. The Department of Commerce has interpreted existing law as precluding public access to death data submitted to the DMF by the states. Non-state data is available if certain Department of Commerce criteria are met. Our inability to access a complete DMF data file impedes the advancement of important research and quality improvement initiatives.

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We have pursued other avenues to obtain death information, but a complete DMF continues to be the most reliable source of this information. For example, the Centers for Disease Control and Prevention maintains the National Death Index (NDI), which is frequently referenced as an acceptable alternative to the DMF data. NDI data is not currently a viable option for clinical registries for several reasons. First, despite recent and continuing enhancements, the data in the NDI are not updated in a timely manner. Second, the pricing structure for access to NDI data is cost prohibitive. Lastly, NDI research criteria exclude the quality improvement efforts currently conducted utilizing clinical registries. There are no other reasonable options for obtaining death information for research and quality improvement purposes.

Our organizations have a legitimate and important need for DMF data. Regaining access to the full DMF is essential if we are to continue to work to improve patient care and outcomes, as well as potentially lower health care costs by identifying the most efficient and effective procedures.

Thank you for considering our comments regarding access to the DMF. We look forward to working with you to ensure clinical data registries have the tools to continue their crucial research and quality improvement activities. Please contact Courtney Yohe at (202) 787-1222 or by email cyohe@sts.org if you have any questions.

Respectfully,

THE SOCIETY OF THORACIC SURGEONS
AMERICAN ACADEMY OF NEUROLOGY
AMERICAN ACADEMY OF PHYSICAL MEDICINE AND REHABILITATION
AMERICAN ASSOCIATION OF NEUROLOGICAL SURGEONS
AMERICAN COLLEGE OF EMERGENCY PHYSICIANS
AMERICAN COLLEGE OF GASTROENTEROLOGY
AMERICAN COLLEGE OF SURGEONS
AMERICAN GASTROENTEROLOGICAL ASSOCIATION
AMERICAN JOINT REPLACEMENT REGISTRY
AMERICAN SOCIETY OF CLINICAL ONCOLOGY
AMERICAN SOCIETY OF NUCLEAR CARDIOLOGY
AMERICAN SOCIETY OF PLASTIC SURGEONS
AMERICAN UROLOGICAL ASSOCIATION
ANESTHESIA QUALITY INSTITUTE/AMERICAN SOCIETY OF ANESTHESIOLOGISTS
SOCIETY OF NEUROINTERVENTIONAL SURGERY