

The Society of Thoracic Surgeons

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June 1, 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: Expanding Access to the Death Master File through the Stopping Improper Payments to Deceased People Act (S.1073)

Dear Chairman Johnson and Ranking Member Carper:

On behalf of The Society of Thoracic Surgeons (STS), I write to express our appreciation for the introduction of the Stopping Improper Payments to Deceased People Act (S.1073), which acknowledges the crucial need for expanded access to a complete Social Security Death Master File (DMF). I hope there is an opportunity for this legislation to recognize other legitimate uses of DMF data, including entities that use death data for the advancement of clinical research and health care quality improvement.

Founded in 1964, STS is an international not-for-profit organization representing more than 7,000 cardiothoracic surgeons, researchers, and allied health care professionals in 90 countries who are dedicated to ensuring the best surgical care for patients with diseases of the heart, lungs, and other organs in the chest. The mission of the Society is to enhance the ability of cardiothoracic surgeons to provide the highest quality patient care through education, research, and advocacy.

The Society developed the STS National Database in 1989 as an initiative for quality improvement and patient safety. The STS National Database has three components – Adult Cardiac, General Thoracic, and Congenital Heart Surgery. The Society has also been able to create a data repository to track patient safety and real-world outcomes related to transcatheter aortic valve replacements through a partnership with the American College of Cardiology (ACC) known as the STS/ACC TVT RegistryTM. Because surgeons typically provide a single episode of care, our registry is not able to collect longitudinal health information on the patients STS members treat. However, prior to November 2011, when the Department of Commerce interpreted existing law

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as precluding public access to death data submitted to the DMF by the states, STS was able to purchase access to DMF data so that we could confirm patients' life status over time. Research based on this information improves surgical outcomes, helps to inform shared decision-making with patients and their families, and enhances the quality of patient care. We are aware that death data which are not state-reported are available if certain Department of Commerce criteria are met, however, the "limited access" DMF is not sufficient for our needs. Our inability to access a comprehensive DMF cripples our ability to advance our quality and research initiatives that are designed to improve the delivery of care.

We have pursued other avenues to obtain death information, but a complete DMF continues to be the most reliable source. 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 are not currently a viable option for several reasons. First, despite recent and continuing enhancements, the data in the NDI are not updated in a timely manner. Final NDI files are typically 1-2 years behind. Second, the pricing structure for access to NDI data is cost prohibitive, which makes the less accurate, early-release program for the NDI inaccessible as well. Lastly, NDI research criteria exclude the quality improvement efforts currently conducted utilizing clinical registries. For similar reasons, we are not able to establish contracts with each individual state/territory that reports to the DMF, and we are not aware of any viable private sector options or other non-federal sources to retrieve the information. Access to the complete DMF would enable the Society to once again track longitudinal patient outcomes and provide information on the long-term efficacy of surgical treatments as well as increase awareness of mortality and morbidity indicators.

The Society is also mindful of concerns regarding the security of personal information found in the DMF. The STS National Database is subject to rigorous privacy protocols that comply with the Health Insurance Portability and Accountability Act standards, the Federal Information Security Management Act, and other privacy and security regulations. We remain committed to enhancing patient safety by improving care in the operating room and protecting patients' privacy and security. We are happy to discuss how our efforts can further contribute to the overall goals of this legislation.

Thank you for considering our comments regarding renewed access to the comprehensive DMF which is of vital importance to our changing health care system. Should you have any further questions or if you would like to discuss this issue further, please contact Courtney Yohe, Director of STS Government Relations at 202-787-1222, or by e-mail cyohe@sts.org.

Sincerely,

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Mark S. Allen, MD President