



Lifespan

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February 15, 2024

Representative Susan R. Donovan
Chair
House Health and Human Services Committee
82 Smith Street
Providence, Rhode Island 02903

Government Relations

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David A. Balasco, Esq.
Vice President

RE: H7301 – An Act Relating to Health and Safety – Licensing of Healthcare Facilities

Dear Chair Donovan:

We write to express our strong support for H.7301, that aligns Rhode Island law with federal law concerning deidentified data sharing which will enhance our ability to conduct medical research. This seemingly small revision to existing statute will have a tremendous impact on vital research while still ensuring patient privacy. Areas of critically necessary research include spinal cord injuries, neurological disease, cancer, improving ICU care, and breathing failure.

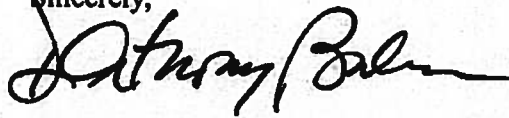
Rhode Island patient privacy statutes are some of the strictest nationwide and more comprehensive than federal law which effectively prevents waiver of consent for research purposes. In contrast, federal law allows for the sharing of deidentified data for research. What this means is that Rhode Island-based scientists are prohibited from contributing anonymized data to other state and national databases. The use of these databases assists multi-institutional research efforts in cutting edge areas. Our exclusion occurs because for us to utilize aggregated data from other states we must in turn share our data, which is prohibited. Put simply, Rhode Islanders are excluded from national studies informing treatment and prevention of critical illness, including registries that determine national clinical guidelines.

One clear example is in oncology research since bladder, lung, endometrial, breast, and prostate cancers are more prevalent in Rhode Island. Our scientific research benefits by allowing us to understand the why of cancer itself, the why of individual responses to treatments, and finding the effective treatments. Successful research necessitates a review of very large amounts of patient data, a collaboration hindered by current law.

To ensure that we keep pace with research in other states we must revise this statute. Importantly, the safeguards in federal law will still apply. In addition, research will still be reviewed by the institutional review boards (IRBs), and in most cases, consent would still be required. Research involving review of medical records that are deidentified is low risk and is typically exempt from new consent procedures for each reviewed record. It is important for Rhode Island research that this minimal risk research be allowed to proceed under a waiver of consent approved by the IRB consistent with federal law.

We appreciate the opportunity to provide our support for this important legislation that will allow our patients to be included in key national research while still protecting their individual rights.

Sincerely,

A handwritten signature in black ink, appearing to read "David A. Balasco". The signature is fluid and cursive, with a large initial "D" and "B".

David A. Balasco, Esq.
Vice President Government Relations