



Wafik S. El-Deiry, MD, PhD, FACP
Director, Legorreta Cancer Center at Brown University
American Cancer Society Research Professor
Director, Joint Program in Cancer Biology
Brown University and Lifespan Cancer Institute (LCI)
Attending Physician, Hematology/Oncology, LCI
Mencoff Family University Professor, Brown University
Associate Dean, Oncologic Sciences
Warren Alpert Medical School, Brown University

Department of Pathology and
Laboratory Medicine
Campus Box G-E5
70 Ship Street, Room 537
Providence, RI 02912
Office: 401-863-9687
Cell: 610-800-2443
wafik@brown.edu

February 15, 2024

Rep Susan R. Donovan
House Health and Human Services Committee
State House
Providence, RI 02903

Re: H7301 Licensing of Healthcare Facilities

Dear Chairwoman Donovan and members of the committee:

Thank you for giving me the opportunity to submit remarks in support of H7 301.

I am Dr. Wafik El-Deiry, Director of the Legorreta Cancer Center at Brown University, and the Associate Dean for Oncologic Sciences at the Warren Alpert Medical School. I am also a practicing medical oncologist at the Lifespan Cancer Institute. I do drug discovery and development research to bring new clinical trials to patients. One of the major advances in cancer treatment has been to recognize that almost every tumor is different from every other tumor and this impacts how patients respond to the treatments they receive.

While a lot of progress has been made in finding out what makes some tumors grow and evade the immune system and resist treatment, we still have a lot to discover as far as predicting who will benefit from certain treatments. Being able to do that will help patients get the right treatments and not waste time with ineffective treatments.

There are certain cancers that are more prevalent in Rhode Island such as bladder cancer, lung cancer, endometrial, breast, prostate cancer among others. We don't know why and we need to understand the causes so we can work to prevent exposures and find appropriate treatments.

In clinical oncology practice these days, patients with cancer get molecular tests to see what's driving the cancers and to determine the most suitable treatments. The medical records have the tumor gene mutations, drugs used to treat and how well they worked for the patients who developed those advanced cancers. Not everyone responds in the same way and so we still need to understand why.

Being able to access large amounts of data in electronic medical records while maintaining confidentiality and abiding by HIPAA privacy rules is necessary to advance our knowledge in these areas. To do this type of medical research in 2023 often requires collaboration with others outside our hospitals or covered entities. This is because in some cases one has to look at large numbers of patients and so data aggregation is important. In other cases, we want to compare communities within Rhode Island to each other or Rhode Island to other states. If we don't share data we also don't get access to data from other states.

As it stands, Rhode Island law may be the strictest in the country as far as data sharing, well beyond federal law that allows sharing of deidentified data. Such research involving review of medical records that are deidentified is low risk and is typically exempt from new consent procedures for each reviewed record. The strict requirements in Rhode Island are disadvantaging the people of Rhode Island by stifling research activities. We have been falling years behind other states in doing needed research to provide better care for the people of Rhode Island. This is hurting our scientists and our patients.

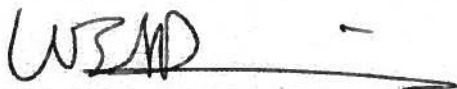


Aligning with what's done in other states would help Rhode Islanders. The research would still be reviewed by the institutional review boards, and in most cases, consent would still be required. But for some research, consistent with federal law, certain research that poses minimal risk would be allowed to proceed under a waiver of consent approved by the IRB.

I am thankful to Representative Ackerman for her leadership and support for this bill. I would like to thank co-sponsors Representatives Donovan, Edwards, Serpa, McNamara, Finkelman, Chippendale, and Shallcross Smith for introducing this legislation to make it easier to conduct medical research that involves data sharing. This is a minor edit of the existing law that ensures patient privacy while allowing important research to proceed. And finally, my thanks to Speaker Shekarchi for his continued support.

Thank you for considering this important Bill.

Sincerely,

A handwritten signature in black ink, appearing to read 'WSEAD', with a long horizontal line extending to the right.

Wafik S. El-Deiry, MD, PhD, FACP
American Cancer Society Research Professor
Director, Legorreta Cancer Center at Brown University
Medical Oncologist, Lifespan Cancer Institute
Associate Dean for Oncologic Sciences, Warren Alpert Medical School