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ACLU OF RI POSITION: OPPOSE

TESTIMONY ON 21 – S 495, AN ACT RELATING TO BUSINESSES AND PROFESSIONS – RHODE ISLAND HEALTH INFORMATION EXCHANGE ACT OF 2008 April 1, 2021

The ACLU of Rhode Island has long been committed to ensuring that public health measures appropriately and vigorously maintain patient autonomy and medical privacy. It is why, for over a decade, our organization has maintained that the inclusion of personal health care and medical information through such platforms as the Health Information Exchange (HIE) must be done on a strictly voluntary basis which centers the self-determination of the patient through an opt-in, rather than an opt-out, system. This legislation would seek to undermine that framework by instead putting the onus on the patient to opt-out of having their personal information automatically stored in this state database. We would like to express our strong opposition to this proposed amendment and urge rejection of the legislation.

Choosing to opt-in to the HIE is a personal decision, and one which should remain firmly within the discretion of the individual patient. There may be many legitimate reasons that an individual may not want their information shared through this state database – they may fear the possibility of a data breach, for example, or they may object to the fact that the HIE generally does not allow for patients to limit or control the types of medical information that go into, or can be accessed through, the HIE. Regardless of the reasoning, the fact remains that when it pertains to patient autonomy, opt-in procedures deliberately put individual patients in the position with the most power to control where and how their personal medical information is stored or disclosed. Amending this statute to instead provide for an opt-out procedure forces an unnecessary burden in front of individuals who place high regard on their own patient confidentiality. We all know that major businesses and websites use an opt-out procedure tracking and many other purposes with the knowledge that inertia will almost always win the day.

We fully understand the state's interest in having as many patients as possible participating in the database and the benefit it can provide them and their doctors. But it is our understanding that the vast majority of patients in Rhode Island voluntarily opt-in to the database. If the benefits are explained to them carefully by their doctor, even more are sure to. But it should always require affirmative consent for patients to waive their privacy rights, rather than require them to affirmatively protect those rights. protect them. An opt-out system creates too great a possibility of unknowing participation in the system and should therefore be rejected.

Thank you for your consideration.