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ACLU OF RI POSITION: AMEND

TESTIMONY ON 26-S 3256, AN ACT RELATING TO HEALTH AND SAFETY -- PUBLIC HEALTH DATA PRIVACY AND PROTECTION ACT May 21, 2026

As an organization that strongly supports protecting the right to healthcare privacy, we appreciate this bill's effort to provide for the confidentiality of a variety of personal data gathered by the Department of Health. At the same time, there is also a strong public interest in having access to various kinds of de-identifiable health data, and we are concerned that – at least at first glance – this bill may inadvertently keep confidential some information that should be public.

Some provisions in the bill appear to conflate, or treat identically, “line-level data,” which by definition includes information that could identify particular individuals, and “reportable disease data,” which more broadly encompasses DOH data relating to “disease reporting, surveillance, investigation, control, or prevention.” Our concern is that the bill gives the DOH absolute and unreviewable control over the release or non-release of all that information.

But giving DOH full discretion to keep secret “reportable disease data” even when such data cannot be connected to an individual strikes us as problematic. To give an example, if this law were in effect during the height of COVID, DOH would have been allowed to withhold any “information,” “record,” or “other data” that could indicate how the Department was performing its “reporting, surveillance, investigation, control or prevention” duties. On this and other critical public health matters, the public, and members of the press on behalf of the public, would have no right to know where outbreaks were occurring or to what degree, except to the extent that the Department was willing to let the public know.

We certainly do not question the good faith or professionalism of those currently working for the Department who handle these matters, but we do not believe that the law should give any agency wide-wielding power to decide when important information like this should be released when there does not appear to be any countervailing privacy interest to consider.

While we recognize that the goal of this bill is to protect patient privacy, a goal we strongly support, we believe that privacy could be protected without the unreasonably broad public records exemption for “reportable disease data” that the bill codifies. We urge the Department and committee to consider amendments to achieve a better balance that protects both privacy rights and the public's right to know, and we have provided the Department with recommendations in that regard. Of course, if we have misconstrued the bill's scope or wording, we welcome being corrected. Thank you for considering our views.