

MEMORANDUM OF CONCERN

A.5370 (Paulin) / S.5732 (Skoufis)

An Act to amend the public health law, in relation to creating the health emergency response data system

The New York State Health Facilities Association | New York State Center for Assisted Living (NYSHFA | NYSCAL), which represents more than 450 skilled nursing and assisted living facilities across New York State, has significant concerns regarding A.5370/S.5732 which would create a “Health Emergency Response Data System (HERDS)” to collect aggregated data related to public health emergencies with the goal of improving overall public health response.

This data, including survey responses, would be made available in relatively “real time” to government entities, health care providers, and the public. However, a similar system, also called “HERDS” (the “Health Electronic Response Data System”) already exists, having evolved in response to public health information requests during 9/11 and Anthrax letter attacks from various conflicting and disparate data systems with the goal of collecting and disseminating data systematically. Since then, the current HERDS has evolved into a centralized data repository for other public health events such as disease outbreaks, statewide emergencies, and weather-related events, as well as other provider data.

While A.5370 specifies that data will be aggregated, it refers to disclosure of geographic location and hospital name. De-identification of protected health information (PHI) under HIPAA must undergo a rigorous and methodical process with certain standards being met. The disclosure of location and hospital, coupled with a stringent 7-day timeframe for providers to disclose the collected data, is troublesome and could have an unintended consequence of jeopardizing patient de-identification, potentially creating more confusion than transparency.

For these reasons, NYSHFA | NYSCAL has significant concerns regarding A.5370/S.5732 as it does not achieve the desired outcome of the sponsors and recommends that appropriate amendments be made to address the concerns outlined within.

March 2023

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