TESTIMONY OF

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L.D. 541, An Act To Improve Health Care Data Analysis

Sponsored by Representative Anne Perry

Senator Sanborn, Representative Tepler and members of the Joint Standing Committee on Health Coverage, Insurance & Financial Services, my name is Karynlee Harrington. I am the Executive Director of the Maine Health Data Organization (MHDO) and am here today to present testimony in support of L.D. 541, An Act To Improve Health Care Data Analysis.

The MHDO's purpose is to create and maintain a useful, objective, reliable and comprehensive health information data warehouse that is used to improve the health of Maine citizens, and to promote transparency of the cost and quality of healthcare in the State of Maine in collaboration with the Maine Quality Forum (MQF). The Maine Health Data Organization is governed by a board of directors which includes representatives from the following stakeholder groups: Payers, Hospitals, Providers, Home Health Care, Consumers, Employers, and Government.

As described in the summary of the bill, Part A addresses issues for both MHDO and its authorized data users which will enhance the value of the data and transparency for many different use cases, including cancer research in the State of Maine. Over the years, MHDO's authorized data users have expressed how valuable and necessary access to different data sets are in their work, including the Death and Cancer Registry data; and MHDO's all-payer claims data (APCD). Because these datasets are not linked our researchers use them, as they describe, in *parallel instead of as an inter-related dataset. Our current structure creates missed opportunities for researches to understand clinically important patient outcomes.* Data linkage is not new, and in fact several states across the country are linking different data sets with their APCD including their cancer registry and vital statistics. For years, Maine has been a leader in understanding the value of creating and maintaining robust health care data sets that can be accessed by a broad group of authorized users while fiercely protecting the confidentiality of individuals. However, we have not been a leader when it comes to data linkage. LD 541, §8715-A, changes that and would give us the opportunity to create a more robust data set for research that will ultimately benefit Mainers. One of MHDO's authorized data users is a Physician Scientist with the Center for Outcomes Research and Evaluation (Maine Medical Center), and she provided the following information in a letter to the committee regarding the value of data linkages:

> "our group completed several analyses studying lung cancer in Maine. We are often unable to determine from the APCD claims data whether someone receiving lung cancer treatment had a recent diagnosis of lung cancer, or whether the malignancy was diagnosed many years ago. Linking to the Maine cancer registry data will allow us to determine the diagnosis time frame, whether the tumor was diagnosed via screening or because of symptoms, the tumor stage and initial treatment course including whether appropriate surgery was carried out. Then, we can use the APCD data to determine if appropriate cancer treatment was completed, and if there are disparities in care due to rurality, insurance type, or other barriers. Further, linkage with death certificate data would allow us to determine if the patient died from their disease or

> another cause, or is still surviving. **Because we will be able to examine care delivery, rurality and socioeconomic status as well as other factors associated with access to care, linkages of these data will be a powerful tool for improving health and health care delivery for the people of Maine."**

Both DHHS and MHDO have invested heavily in creating and managing their data collection, governance, security, confidentiality and data release rules. If the legislature enacts LD 541, it will be critical for the MHDO and DHHS to collaborate on developing a rule to govern the linkage of these data sets, including collection, governance, confidentiality and release rules.

Part A also creates administrative efficiencies for the MHDO by eliminating several annual reports described in section 8712 of MHDO's governing statute that are outdated; and reduces the current mandate that the cost data on CompareMaine be updated two times annually to once annually. These changes will not negatively impact MHDO's mandate to promote the transparency of health care costs; but rather, they will allow the MHDO to focus resources on tasks that will provide more transparency and value for our data users and the public. Part A establishes the MHDO Health Information Advisory Committee; created to assist the MHDO in its mandate to promote the transparency of health care costs and quality data by making recommendations to the MHDO board of directors regarding key health care topics on which the MHDO should report.

Part B of the bill directs the MHDO to develop and maintain a provider database in collaboration with the Department of Health and Human Services which will then be used to populate a service locator tool that will be available on a publicly accessible website. MHDO currently collects data elements on providers in both our claims and hospital data submissions and in Rule Chapter 300, *Uniform Reporting System for Hospital Financial Data,* which includes new provider data elements specific to organizational information from health systems, hospitals and physician practices, both primary and specialty care. We have been working with our data users for over a year, and more recently with MaineCare on the structure of an integrated provider database that unifies all the provider information that MHDO collects.

I look forward to working with the Committee, DHHS and other interested parties during the work session. That concludes my testimony; I am happy to take questions.