TO: Senator Craven, Representative Farnsworth and Members of the Joint Standing Committee of Health and Human Services

FROM: Karynlee Harrington, Acting Executive Director, Maine Health Data Organization

CC: MHDO Board of Directors

Anna Broome, Legislative Analyst

DATE: March 4, 2014

RE: LD 1740

In order to address the issues that have been raised by the Committee, the ACLU and HealthInfoNet we are prepared to add the following provisions to LD 1740:

1. **Privacy and Security:** The board shall adopt rules to ensure privacy and security protections of the data that are at least equivalent to the privacy and security requirements of HIPAA.

1. **Oversight and Notification to individuals:** The rules shall provide a definition of breach and for notification to individual’s equivalent with those of HIPAA.  In addition, in the case of a breach that requires notification to affected individuals, MHDO shall report such a breach to the Joint Standing Committee on Health and Human Services, who may then report it to the Joint Standing Committee on the Government Oversight Committee and/or the Attorney General’s Office.

1. **Individual Complaints:** We will add language to LD 1740 that states if an individual believes that their PHI has been released by MHDO, the board, or an employee of MHDO, in violation of MHDO rules, they may file a complaint with the Joint Standing Committee on Health and Human Services.

1. **Data Use Agreements and Business Associate Agreements**: LD 1740 states…Data releases must be governed by data use agreements that provide adequate privacy and security measures (we will add what follows) including appropriate accountability and notification requirements as in HIPAA business associate agreements.

1. **Fine and Penalties:** The federal government has no jurisdiction over MHDO as we do not meet their definition of a covered entity. The MHDO is accountable to the State. We are proposing that we add language to LD 1740 consistent with the following:

A person or entity that obtains by any means, data or information submitted to, stored by, or disclosed by MHDO and who intentionally or knowingly uses, sells or transfers the data, or attempts to do those things, for commercial advantage, pecuniary gain, personal gain, or malicious harm commits a Class D crime. A separate offense occurs regarding each individual whose information is involved in any of the prohibited acts. Such crimes will be reported to the Attorney General’s office.

Lastly, in the spirit of trying to find a compromise we have offered the following as an alternative to the MHA amendment:

1. The release of identified PHI shall be limited to the data sets that the MHDO currently collects until such time MHDO completes rulemaking on any new types of clinical data.
2. Before collecting any new types of clinical data, MHDO will promulgate rules. Rulemaking regarding the definition, collection, use, and release of clinical data, shall be major substantive rulemaking.

I hope that the additions that we are proposing to include address the issues that have been raised regarding LD 1740. I thank you for your consideration.