

**HealthInfoNet
Portland, Maine**

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Subject: Maine Health Data Organization Board Retreat- Linking Clinical and Claims Data

While I am writing this document from the perspective of the CEO of HealthInfoNet, my comments are intended to highlight broad areas of observation and concern that go beyond HealthInfoNet's specific focus as one stakeholder. My intent in bringing this document forward is to support deliberations by the MHDO Board as it entertains the question of linking person identified clinical data with claims data. My comments reflect lessons drawn from more than thirty years of working with automated clinical and claims data systems in support of direct patient care and clinical performance improvement. My thoughts for the Board's consideration are as follows:

Role of the Patient- The MHDO has already determined that it will introduce an opt out option to enable individuals to decline having their person identified data used for reporting and analytics. However, there needs to be some serious thought given to the challenges and cost of fully engaging and educating Maine residents on what data will be used, how that data will be used, and what the benefits of using this data will be to the individual, both directly and indirectly. At HealthInfoNet, we pride ourselves in maintaining strong consumer support and believe that a great deal of our success has been the result of involving consumers early on in our development of the organization. Linking person identified clinical data from their treating providers to claims data would require extensive work with the consumers to guarantee they are well informed of the process and have the opportunity to support or object to the process. With the recent revelations about the NSA and government engagement in gathering and accumulating personal information, trust will become a significant issue among Maine residents when it comes to the State Government accessing and managing person identified clinical data. HealthInfoNet has struggled since its inception with establishing and maintaining a "trust framework" with health care consumers that enables individuals to feel comfortable that their personal information is being used appropriately and for their benefit. MHDO will confront these same trust issues, and because this initiative will take place in the public arena, MHDO must anticipate that the trust concerns of individuals will be amplified.

Defining Clear and Meaningful Use Cases- Expanding upon the challenges and cost of building a trust framework, it is imperative that the MHDO define and communicate clear and meaningful use cases that fully substantiate why person identified clinical information linked to claims data by a state agency is warranted and in the public's best interest. Since the person identified clinical data will originate from interactions between providers and patients, there needs to be careful thought given to the potential disruption of the care relationship resulting from a patient's fear that information they view as "sensitive" will be communicated to the State Government. As stated in the first section above, these use cases need to clearly specify what person identified clinical data will be used under what circumstances, who will have access to this information, why it is needed, and provide evidence the data is not available through existing sources. When I implemented my first electronic medical record system for a large Maine provider organization in the 1990s, I experienced firsthand the problem of patients being afraid to tell their providers about issues they felt uncomfortable with because a computer was involved. While this level of general fear may have dissipated a bit within the direct patient care experience over the past twenty years, introducing the mandate that person identified clinical data be reported to the State for linkage to claims data in the absence of clearly defined and meaningful use cases will threaten patient communication.

Managing the MHDO Opt Out Process- HealthInfoNet requests that the MHDO Board **NOT** entertain development of an opt out process for person identified clinical or claims data that involves providers (physicians and hospitals) administering the process. The potential for patient confusion with participation in HealthInfoNet versus a potential MHDO data set is too great given that state law already requires providers to notify patients about HealthInfoNet and the option to opt out of inclusion in the statewide exchange.

The Cost of Managing Patient Identified Clinical Data- Managing patient identified clinical data sets originating from multiple provider organizations is both complicated and expensive. The annual operating budget for HealthInfoNet has been between \$5 and \$6.5 million over the past few years. The MHDO Board needs to assume that its operating costs will increase as a result of incorporating person identified clinical data into its portfolio and linking that data to claims data. HealthInfoNet was very encouraged by the results of the technical feasibility study to determine how claims and clinical data might be linked but there were significant technical questions remaining. Those technical issues along with cost estimates and potential revenue sources need to be addressed.