

Legal Review of Health Information Exchange in the New England States

Michelle M. Winchester, JD¹; Monica R. McClain, PhD²

Many of the current improvements to health care delivery are dependent upon technology, creating solutions that require the exchange of medical record information among and between providers, health care organizations and public health programs. Genetic practitioners within the New England Genetics Collaborative (NEGC) have begun to collect and analyze clinical information that will increase the ability to perform outcomes analyses to improve patient care via quality improvement initiatives. The NEGC is committed to the highest standards of health information privacy and security, and must ensure that participants are knowledgeable of legal protections as related to health information technology and exchange. As genetic information is integrated into new technologies, the laws and regulations that impact work conducted in clinical and public health settings must be assessed before projects expand efforts into the realm of complete and complex health information exchange. This assessment was completed by Michelle Winchester, an attorney with expertise in health care. A review of laws and regulations in all New England states specifically related to the exchange of health data that may contain genetic information was conducted. Barriers, impediments and challenges to conducting health information exchange activities within and between states were identified. Particular attention was focused on the activities of the NEGC related to the formation of registries, data sharing and exchange between non-administrative or fiscally related organizations and patient consent requirements. An assessment of national and regional legal and policy analyses in these areas were included, as applicable.

The treatment of genetic health information as sensitive information that is subject to enhanced protections is a standard found both in state and federal law. The wisdom of that treatment has been and remains a subject of much debate. Clearly, even the six New England states cannot reach agreement on how health care providers should treat genetic information—one state having no law on the subject, two states treating genetic information in the same manner as all other health information, and three states requiring written consent (or “informed” written consent) prior to disclosure. In the states that require written consent for disclosure, the common exception to the requirement is newborn screening (NBS) information obtained pursuant to state NBS requirements. Given the language of these laws, the extent of the NBS exception may be limited to information use and disclosure explicitly identified in state law and may not extend to testing or disclosure performed secondary to or subsequent to the required newborn screen and initial report or to the initial treatment referral. It should also be noted that privacy concerns are not limited to genetic information but also extend to the general medical record. The full report may be accessed at: <http://www.negenetics.org/Resources/professionals/default.aspx>.

¹ University of New Hampshire School of Law, Durham, NH

² New England Genetics Collaborative, University of New Hampshire, Durham, NH